Views of People with Mental Illness on Assessment of, and Support During, Diminished Capacity.

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A thesis submitted to fulfil the requirements of the degree of Master of Social Work

University of Otago

Dunedin

New Zealand

2015

Abstract

Definitions of incapacity are socially constructed, resulting in inconsistency in judicial approaches to supporting people with mental illness with diminished capacity in New Zealand. Debates on the nature of incapacity and decision-making during diminished capacity have largely occurred in academic, legal and professional arenas, yet people with mental illness are uniquely able use their experience of diminished capacity to contribute to these debates.

This mixed-methods, exploratory study sought to ascertain the range of views held by people with mental illness on: 1. factors deemed relevant to capacity assessment, 2. who should be involved in capacity assessment and decision-making, and 3. how decisions should be made during diminished capacity. Twenty-eight people participated in qualitative focus groups and / or individual interviews in Dunedin. Constant comparison analysis, content analysis, keyword-in-context and quantitative statistical analysis were used to analyse data.

There was no significant consensus in response to the research questions. Instead, participants argued for holistic, individualised assessment and decision-making that accounts for their individuality, their context and their experience. Participants wanted choice in who was involved, often preferred more than one person, and wanted these people to have knowledge of them, their illness and their sense of 'control'. Significant barriers to involving others were identified, often culminating in stigma and social isolation. Participants endorsed their own involvement in decision-making and supported decision-making in the first instance. Beyond this first preference, participants favoured an individualised menu of decision-making options. Several requested decisions be overridden should these prove 'risky.' A spontaneous finding highlighted the importance of relational autonomy in facilitating capacity, whether retained or diminished. It is recommended that current legislation be reviewed to allow flexibility and choice in capacity assessment, decision-making, and involving others, and that people with mental illness be encouraged to engage in discussion on principles guiding decision-making should their capacity be diminished.

Acknowledgements

First and foremost, I would like to thank those who took part in this research project. I am humbled by your openness, insight, understanding, and humour. I hope I have done your views justice.

I would like to thank the people and organisations who allowed me to access their groups and facilities. In these times, when pressures are high and resources are low, I appreciate that my presence cannot always have made your jobs easier. I am also grateful for your ringing endorsement of my project; I suspect fewer people would have chosen to participate had it not been for your support.

To my research supervisor, Amanda Barusch, many thanks for your insights and comments; always on point, unfailingly illuminating, and frequently reminding me that while something may be interesting, it isn't always relevant! Also for your tireless editing, re-editing, and final editing of the various iterations of this thesis. Fortunately it got a little bit shorter with every re-reading. To Kate Scott, from Health Research South, for agreeing to put her name to a project about which she knew little, for a person about whom she knew even less; many thanks.

Finally, to Philip, for tolerating the paper hurricane that descended upon our office, for the hugs to counteract the headaches, and for the unavoidable deadline so I finally got this thesis completed.

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Chapter 1: Assessing and Intervening in Times of Incapacity

Are we competent to support, empower and protect people with diminished capacity[1]? Specifically, do we appropriately attend to the needs of people with mental illness, whose capacity may fluctuate (Coverdale, 1996; Ryan, 2011)? There are a range of judicial options in New Zealand legislating allowable interventions when someone's capacity is diminished. Yet ideas about what is capacity and how those with diminished capacity should be supported are hotly contested (Nys, Welie, Garanis-Papadatos, & Ploumpidis, 2004), and New Zealand legislation is inconsistent in its approach.

This chapter gives a brief overview of understandings of, and debates on, the nature of incapacity and approaches to supporting people with diminished capacity. Current New Zealand legislation is reviewed in the context of these debates and shown to be inconsistent. Shortcomings of studies ascertaining the views of people with mental illness on the nature of incapacity and their preferred decision-making approaches, should they lack capacity, are highlighted. In light of this background, it is argued that people with mental illness are uniquely able, when they have capacity, to reflect on what it is like to lack capacity. Specifically, that they will have unique insights into what elements are relevant for capacity assessment, how decision-making should occur when capacity is diminished, and who should be involved in these processes. Amidst calls by commentators to review existing legislation in light of its inconsistencies (Atkin, 2011;

[1] A quick note on the use of 'capacity' versus 'competence': Strictly speaking, capacity is a distinct legal concept applied to a specific decision (Nys, Welie, Garanis-Papadatos, & Ploumpidis, 2004), whereas competence relates to the impact of one's psychological and emotional state on decision-making in general (Atkin, 1997). However, capacity and competence are often used interchangeably (Nys *et al.*, 2004; Skegg, 2011); this document will do the same.

Bell & Brookbanks, 2005; Court, 1996; Ministry of Health, 2008; O'Brien, 2010), it is vital that the voices of people with mental illness be included in these debates.

1.1 Measuring (In)capacity

> Determining whether or not a patient is mentally capable of making a decision . . . is one of the most conceptually and ethically challenging areas of clinical practice.
>
> (Banner, 2012, p. 1038)

1.1.1 The Development of Assessment Tools

Historical development. Despite the use of capacity in legal, medical and social arenas, the lack of a clear definition (Garrison, 2007) results in ongoing debates as to its nature and the factors to be considered in its assessment.

Traditionally, incapacity was considered a global, all-encompassing condition understood categorically (Bell & Brookbanks, 2005; Berghmans, 2001; Buchanan & Brock, 1989; Court, 1996)– people had either full capacity or none (Garrison, 2007; Nys *et al.*, 2004). Diagnostic labels were considered indicative of a person's capacity and large groups of people, such as the mentally ill, were excluded from all aspects of decision-making. This is termed a 'status' approach (Carney, 2012; Nys *et al.*, 2004; Okai *et al.*, 2007).

A number of factors have conspired to change this, notably the growing recognition of the principle of autonomy (Atkin, 1997; Bell & Brookbanks, 2005; Berghmans, 2001; Carney, 2012; Carney & Tait, 1998; Oliver, 1997). Autonomy as a principle guiding medical intervention is fairly new (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Dresser, 1993; Freyenhagen & O'Shea, 2013; Hanssen, 2004; Levine, 1991; Ruhnke *et al.*, 2000); in the past doctors acted paternalistically to further what they considered the patient's best interests (Atkin, 1997; Bell & Brookbanks, 2005;

Coverdale, 1996; Donnelly, 2009; Wand & Chiarella, 2006). With the acknowledgement of patient autonomy came a concurrent right to refuse treatment and the concept of informed consent (Beauchamp & Childress, 2006); subsequently a need arose for measures to assess whether someone was capable of giving this consent (Beauchamp & Childress, 2009; Roberts, 2002, in Bell & Brookbanks, 2005). This latter provided the impetus to develop measures of capacity.

Over time, most jurisdictions have moved towards an understanding of incapacity as decision-specific and variable (Berghmans, 2001; Buchanan & Brock, 1989; Carney, 2012; Court, 1996; Nys *et al.*, 2004; O'Brien, 2010; Ryan, 2011), fluctuating throughout the lifespan and affected by a range of variables (Carney, 2012; Court, 1996; Nys *et al.*, 2004). This change in understandings of capacity has led to a 'presumption of competence' (Buchanan & Brock, 1989; Skegg, 2011), recognising that even during a psychiatric crisis people often retain some capacity (Nys *et al.*, 2004). With incapacity no longer tied to diagnosis, attention turned to the processes used to reach a decision.

Current assessment models – The MacCAT. Currently a functional, 'cognitive' approach, the MacArthur Competence Assessment Tool (MacCAT) (Appelbaum & Grisso, 1995; Appelbaum & Roth, 1982; Grisso & Appelbaum, 1998; Grisso, Appelbaum, & Hill-Fotouhi, 1997; Grisso, Appelbaum, Mulvey, & Fletcher, 1995) is the most commonly accepted method of capacity assessment (Bell & Brookbanks, 2005; Coverdale, 1996; Garrison, 2007; Lamont, Jeon, & Chiarella, 2013; Nys *et al.*, 2004; O'Brien, 2010; Okai *et al.*, 2007).

In developing the MacCAT, Appelbaum and colleagues reviewed case law and identified four, discrete, measurable standards used to make legal judgements of capacity (Appelbaum & Grisso, 1995; Appelbaum & Roth, 1982; Grisso & Appelbaum, 1998, 2007; Grisso *et al.*, 1997, 1995):

1. The ability to *communicate* a choice,
2. The ability to *understand* relevant information,
3. The ability to *reason* with, or *evaluate*, this information, and
4. The ability to *appreciate* the significance of this information to one's situation

Communicating a choice requires the person to express a (minimally consistent) decision, whether verbally or otherwise. The ability to *understand* relates to the person's comprehension of the decision and the benefits and risks of available options. *Reasoning*, or *evaluation*, involves the cognitive manipulation of this information, with assessors judging whether the decision follows logically from the individual's explanations. Finally, appreciation requires individuals to recognise information as personally relevant to themselves and their situation. This tool, initially used in research settings, was later adapted to assess medical decisions and called the MacArthur Competence Assessment Tool – Treatment (MacCAT-T) (Grisso & Appelbaum, 1998; Grisso *et al.*, 1997). In a 20 minute, semi-structured interview, the MacCAT-T asks the individual to make a choice and explain his or her rationale, with questions targeted to assess understanding, reasoning, and appreciation (Grisso & Appelbaum, 1998; Grisso *et al.*, 1997).

Although multiple tools have been developed to measure capacity (Lamont *et al.*, 2013; Okai *et al.*, 2007), they generally contain one or more components of the MacCAT; a review by Lamont *et al.*, (2013) of 17 assessment tools found 59 percent utilised all four domains of the MacCAT. The MacCAT and these derivatives are generally referred to as 'descriptive' (Charland, 2001, in Banner, 2012), 'cognitive' models due to their measurement of practical reasoning (Berghmans, 2001; Garrison, 2007; Wand & Chiarella, 2006) and it is argued these cognitive models allow capacity to be objectively assessed (O'Brien, 2010). A meta-analysis reported that "although diverse measures of mental capacity have been used, they are capable of making fairly consistent estimates [of incapacity]" which are statistically more reliable "than cardiologists interpreting exercise electrocardiograms, radiologists interpreting mammograms or haematologists reading peripheral blood films" (Okai *et al.*, 2007, p. 295).

However, there is some criticism of cognitive approaches to assessment. For example, Lamont *et al.* (2013) found inconsistencies in what was measured among tools using MacCAT domains, particularly in appreciation and reasoning. Further, some believe cognitive models miss key variables which may not be cognitively based but nevertheless influence decision-making, this point is further discussed in Part 1.1.2.

Incapacity and mental illness. Numerous studies measuring the prevalence of incapacity have concluded that people can no longer be deemed to lack capacity simply by virtue of mental illness (Banner, 2012; Court, 1996; Coverdale, 1996; Ryan, 2011). For example, a meta-analysis not only found that "a sizeable proportion – usually the majority" of psychiatric inpatients had capacity, but that "the frequency of incapacity did not differ greatly from that in general hospital inpatients" (Okai *et al.*, 2007, p. 295). When people with mental illness did lack capacity, this was correlated with psychosis (Amer, 2013; Jenkins & Williamson, 2012; Okai *et al.*, 2007), illness severity (Okai *et al.*, 2007), involuntary admission and treatment refusal (Owen *et al.*, 2008, in Jenkins & Williamson, 2012; Okai *et al.*, 2007).

Instead, it is recognised that although mental illness may not *necessitate* incapacity, mental state can *influence* it, and people with mental illness may have 'chronically and variably impaired' capacity, (McCulloch *et al.*, 1992, cited in Coverdale, 1996). For example:

- *Communication* can be affected in cases of catatonia or mutism (Appelbaum & Grisso, 1995; Appelbaum & Roth, 1982). It can also be disrupted when extreme thought disorder renders decisions unintelligible (Coverdale, 1996; Grisso *et al.*, 1997; Torke, Alexander, & Lantos, 2008) or when a person's choice fluctuates "to such an extent that a course of treatment cannot be implemented before they change their minds again" (Appelbaum & Grisso, 1995, p. 109; Bell & Brookbanks, 2005).
- The ability to attend to and *understand* information can be interrupted by delusions, hallucinations or thought disorder (Amer, 2013; Appelbaum & Grisso, 1995; Appelbaum & Roth, 1982; Coverdale, 1996; Grisso *et al.*, 1995; Owen *et al.*, 2013).
- *Reasoning* can be disrupted by paranoid or grandiose ideas, delusions, or affective disorders disrupting cognitive processes and the weighing of consequences (Appelbaum & Roth, 1982; Clausen, 2014; McKenna, Simpson, & Coverdale, 2007; Meynen, 2011).
- Finally, *appreciation* can be undermined by denial, or lack of insight (Appelbaum & Grisso, 1995; Appelbaum & Roth, 1982; Bell & Brookbanks, 2005; Coverdale, 1996; Grisso *et al.*, 1995). Others contend appreciation

refers to the individual's ability to "feel" a decision's implications, and contend this can be impaired by fear, delusion, or depression (Buchanan & Brock, 1989; Elliott, 1997; Garrison, 2007; Grisso & Appelbaum, 2007, 2007; Paulus & Yu, 2012).

1.1.2 Debates on the Nature of Capacity and its Assessment

Despite its prevalence, there are numerous critics of cognitive models of capacity. Debate focusses on three fronts:

First, some argue cognitive models fail to consider non-cognitive factors undermining decision-making (Brudney, 2009; Garrison, 2007; Sjöstrand, Eriksson, Juth, & Helgesson, 2013; Sjöstrand & Helgesson, 2008) such as emotionality (Banner, 2012; Breden & Vollmann, 2004; Bursztajn, Harding, Gutheil, & Brodsky, 1991; Charland, 1998; Drane, 1985; Elliott, 1997; McKenzie & Watts, 2011, in Jenkins & Williamson, 2012; Meynen, 2011; Nys *et al.*, 2004; Paulus & Yu, 2012; Tan, Hope, & Stewart, 2003), unusual beliefs (Banner, 2012; Berghmans, 2001; Elliott, 1997; Garrison, 2007; Grisso & Appelbaum, 1998) and distorted values (Banner, 2012; Brock & Wartman, 1990; Buchanan & Brock, 1989; Charland, 1998; Karel, Moye, Bank, & Azar, 2007; Kontos, Freudenreich, & Querques, 2013; Lamont *et al.*, 2013; Tan *et al.*, 2003; Tan, Hope, Stewart, & Fitzpatrick, 2006).

Second, some disagree on whether capacity assessment should prioritise past, present or future selves, and question how this should be decided (Craigie, 2013; Donnelly, 2009; Dresser, 1993; Dworkin, 1993; Meynen, 2011; Pellegrino, 1994; Sjöstrand, 2013).

Third, legal capacity remains a threshold concept (Buchanan & Brock, 1989; Garrison, 2007; Nys *et al.*, 2004; Sjöstrand, 2013), and there is debate about whether the border between capacity and incapacity should be based on the complexity of the decision or the severity of its consequences (Brock, 1991; Buchanan & Brock, 1989; Buller, 2001; Cale, 1999; Skene, 1991; Wicclair, 1991a, 1991b, 1999; Wilks, 1997, 1999).

Capacity, autonomy, and authenticity. Critics claim cognitive models of capacity are 'parsimonious' (Banner, 2012; Garrison, 2007), focussing wholly on the internal rationality of a person's decision (Berghmans, 2002, in Nys *et al.*, 2004) without considering non-cognitive factors – "a patient may be confused, combative, depressed or despairing. But if she can accurately describe the treatment choice, its corollary risks, and its potential benefits to her, she is competent to consent" (Garrison, 2007). Instead, these critics argue there is a distinction between a decision demonstrating capacity using a cognitive model and an *autonomous* decision deriving "from the person's own values and beliefs . . . not . . . internal or external constraints" (Beauchamp *et al.*, 1984, cited in Coverdale, 1996, p. 62).

There are multiple conceptualisations of autonomy. At its most basic level, autonomy refers to 'individual autonomy' (DuBois, 2008; Ho, 2008; Jenkins & Williamson, 2012; Kontos *et al.*, 2013; Pellegrino, 1994; Tauber, 2003) and people's ability to decide for themselves (Beauchamp & Childress, 2009; Bell & Brookbanks, 2005; Dworkin, 1993; Garrison, 2007; Kontos *et al.*, 2013; Pellegrino, 1994). However, a broader view of autonomy maintains that it is "a distortion of the idea of autonomy to equate it with total independence from . . . others in making treatment decisions" (Pellegrino, 1994, p. 50), and that internal processes can influence autonomy by undermining the 'authenticity' of a person's decision (Beauchamp & Childress, 2009; Brudney, 2009; Freyenhagen & O'Shea, 2013; Garrison, 2007; Hope, Tan, Stewart, & Fitzpatrick, 2011; Sjöstrand, 2013; Sjöstrand & Helgesson, 2008; Skegg, 2011; Tan *et al.*, 2003, 2006).

The first argument points to the concept of *relational autonomy.* Relational autonomy acknowledges that humans exist within communities and social influences shape decision-making (Kontos *et al.*, 2013; Martin & Hickerson, 2013; Pellegrino, 1994; Sjöstrand, 2013; Tauber, 2003). It recognises that decisions are not made in isolation; justifications for decisions often reference their impact on others (Ho, 2008), and "deciding for oneself is not something that one typically does by oneself" (Martin & Hickerson, 2013, p. 203). Cultural arguments are also made for relational autonomy; in some cultures involvement of, and deferral to, others in decision-making is integral to competent decision-making (Leever, 2011; Minkoff, 2014).

The second argument relates to one's *authenticity.* Authenticity refers to a person's sense of self, of his or her decisions as arising from "deeply set values, aims and interests" (Brudney, 2009; Sjöstrand, 2013; van Willigenburg & Delaere, 2005, in Sjöstrand & Helgesson, 2008, p. 116) and the idea that 'the wants and desires I act upon are my own' (Sjöstrand, 2013). This references the autonomy-negating effect of external influence, but goes further to suggest a sense of internal coherence. Authors citing authenticity argue for three factors to be included in capacity assessment; emotionality, changes in beliefs and distorted values. Although linked, they are addressed separately here.

Emotionality. Most people can identify times when extreme emotional states have influenced decision-making. Common aphorisms such as 'blinded by rage' or 'paralysed by fear' reference this experience. Yet emotionality is not explicitly addressed in any standard capacity assessment tool. Both the presence of excessive emotions and the complete absence of emotions are cited as reasons for including emotionality in capacity assessment.

"Extreme" emotions. Some cite the potential for emotions to "interfere" with decision-making processes (Rivers v Katz, 1986, in Garrison, 2007, p. 798), arguing that capacity assessment must identify decisions "disproportionately influence[d]" by extreme emotions (Banner, 2012, p. 1042; Breden & Vollmann, 2004; Bursztajn *et al.*, 1991; Charland, 1998; Elliott, 1997; Garrison, 2007; Meynen, 2011; Paulus & Yu, 2012).

Extreme emotions could affect decision-making by altering the evaluation of future consequences (Banner, 2012; Breden & Vollmann, 2004; Bursztajn *et al.*, 1991; Charland, 1998; Elliott, 1997; Garrison, 2007; Lazarus, 1991; Meynen, 2011; Paulus & Yu, 2012). For example, research demonstrates people with depression may be unable to 'feel' possible future benefits as personally relevant and instead selectively attend to negative consequences (Bursztajn *et al.*, 1991; Elliott, 1997; Paulus & Yu, 2012). Similarly, anhedonia, an inability to experience pleasure and enjoyment, can alter the way losses and gains are balanced (Paulus & Yu, 2012). Other, more subtle effects relate to one's emotional attachment to certain "unhealthy" conditions (Garrison, 2007; Tan *et al.*, 2003); for example, a person with schizophrenia may be emotionally invested in believing he or she is the son of God. Over time, this persistent erroneous decision-

making process could alter belief systems (Charland, 1998; Elliott, 1997; Paulus & Yu, 2012).

Emotions can also undermine an individual's *control* over decisions (Freyenhagen & O'Shea, 2013). This is related to the notion of first-order versus second-order desires ('what I want' versus 'what I want to want') (Appelbaum, 1998; Hope *et al.*, 2011; Sjöstrand, 2013). For most people, emotions signal incompatibility between these desires, resulting in an attempt to resolve the conflict (Appelbaum, 1998), but for some this can be overwhelming. For example, in compulsive disorders the distress associated with obsessive thoughts compelling a decision to act (a first-order desire) can cause a person to feel 'forced' to engage in the act, despite a second-order desire not to do so (Freyenhagen & O'Shea, 2013).

The absence of emotion. Conversely, Charland (1998), a key proponent for the inclusion of emotionality in capacity assessment, suggests that decision-making requires an emotional component. Citing Lazarus' (1991) Cognitive Appraisal Theory, he argues that without emotional *appraisal* – defined as the "continuing evaluation of the significance of what is happening for one's well-being" – "knowledge is cold . . . [but] when knowledge touches on one's personal well-being . . . it is hot, or emotional" (Lazarus, 1991, p. 144). Consequently, although a person may realise a decision is relevant on an abstract, intellectual basis, "emotive capacities" are crucial to fully appreciate the decision; "individuals cannot be said to appreciate fully the choices they face unless the choices mean something to them personally" (Charland, 1998, p. 367). He subsequently questions why "the cognitive capacities that underlie emotion should be unilaterally excluded from the cognitive capacities that underlie competence" (p.364).

Certainly, the absence of any emotional appraisal – if nothing *personally means* anything and individuals simply *don't care* – could undermine capacity (Appelbaum, 1998; Charland, 1998). Patients with areas of frontal lobe damage can still perform adequately on tests of cognition and decision-making, but severe deficits in their experience of emotions mean they do not care 'enough' about the decision; "they appear preternaturally calm and detached, even when discussing material with striking emotional content" (Appelbaum, 1998, p. 383). Consequently, "decision making can be impaired subtly by disorders in which a person is perfectly capable of fulfilling the

capacity criteria as an abstract exercise . . . while attaching no affective significance to the process or outcome" (Banner, 2012, p. 1042).

Beliefs. Beliefs form an important part of decision-making, underpinning our evaluation of likely outcomes (Brock & Wartman, 1990; Coverdale, 1996; Paulus & Yu, 2012; Tan *et al.*, 2006).

The potential for emotions to influence a person's belief system has already been raised (Coverdale, 1996; Elliott, 1997; Paulus & Yu, 2012), however perhaps the belief most influential in capacity assessment is belief in one's diagnosis – one's level of insight. A failure to recognise the nature and severity of one's illness is considered by many to indicate incapacity to make decisions regarding that illness. (Appelbaum & Grisso, 1995; Bell & Brookbanks, 2005; Garrison, 2007; Grisso *et al.*, 1995). Accordingly, patient insight is deemed "highly relevant" to assessors (Diesfeld, 2003, in Bell & Brookbanks, 2005, p. 228). Yet inclusion of insight is controversial, as psychiatrists themselves often disagree on diagnosis and treatment approaches (Banner, 2012; Berghmans, 2001).

Rather than focussing on insight, some authors suggest assessment should identify "rigidly held" (Grisso *et al.*, 1995, p. 128) or patently untrue beliefs (Banner, 2012) something they consider already accounted for by the *reasoning* or *appreciation* components of standard cognitive models (Grisso & Appelbaum, 2007; Grisso *et al.*, 1995). However, beliefs are subjective things, built upon experience and personal evaluations (Brock & Wartman, 1990; Coverdale, 1996; Paulus & Yu, 2012; Tan *et al.*, 2006). Thus, although a person's beliefs when depressed could be considered inauthentic as they are different from when the person is well (Elliott, 1997), it is hard to say whether the beliefs regarding treatability held by a person with longstanding depression, where numerous interventions have failed, is distorted. This begs the question, who decides when beliefs are 'patently untrue'?

Values. Decision-making is a complex, multivariate process involving a range of personal, familial and cultural values (Charland, 1998; Lamont *et al.*, 2013). In proposing the inclusion of a values component in capacity assessment, three motives are put forward; first, to ensure decisions are consistent with values (Banner, 2012; Berghmans, 2001; Buchanan & Brock, 1989; Charland, 1998; Donnelly, 2009; Sjöstrand, 2013; Sjöstrand & Helgesson, 2008); second, to identify 'distorted' values (Banner, 2012;

Freyenhagen & O'Shea, 2013; Pellegrino, 1994; Sjöstrand & Helgesson, 2008; Tan *et al.*, 2003); and third, to increase transparency (Banner, 2012; Freyenhagen & O'Shea, 2013; Kontos *et al.*, 2013).

In determining the authenticity of a decision, a value assessment would verify whether there is a reasonable relationship between people's enduring value system and their decisions – a degree of internal rationality (Banner, 2012; Berghmans, 2001; Buchanan & Brock, 1989; Charland, 1998; Donnelly, 2009; Sjöstrand, 2013; Sjöstrand & Helgesson, 2008). The assertion that values are enduring (Buchanan & Brock, 1989; Charland, 1998; Freyenhagen & O'Shea, 2013; Grisso & Appelbaum, 2007) also suggests any sudden changes could be considered inauthentic. This focus on temporal and internal consistency would identify apparently reasonable decisions that are either inconsistent with the individual's stated values or based on values differing widely from his or her norm (Brock & Wartman, 1990).

However, what if someone's values are stable over time, but appear to others to be distorted? In raising this question, the case of a patient with anorexia is often cited. In anorexia the illness can become valued of itself (Tan *et al.*, 2003, 2006). This valuing of anorexia, considered by some to be an illness-driven distortion, results in a weighing of risks and benefits which passes standard cognitive capacity assessments (Tan *et al.*, 2006) but which are considered unusual by outsiders (Banner, 2012; Brudney, 2009; Pellegrino, 1994; Tan *et al.*, 2003, 2006). This has fed the argument that people with anorexia fail to demonstrate decisional capacity due to a value system distorted by the "complex interplay between positive evaluations associated with the anorexic identity, self-control and thinness, distorted beliefs about body shape and extreme fears about weight gain, to name but a few factors" (Tan *et al.*, 2008, in Banner, 2012, p. 1042; Pellegrino, 1994; Sjöstrand & Helgesson, 2008; Tan *et al.*, 2003). Yet, the plurality of human experience (Buchanan & Brock, 1989; Sjöstrand *et al.*, 2013; Sjöstrand & Helgesson, 2008) means identifying 'distorted values' is a normative judgement (Freyenhagen & O'Shea, 2013) holding people to the 'tyranny of the majority'.

Finally, capacity assessments are often requested when there is conflict between patients' values and those of their doctor; "when health is the end-all and be-all . . . any treatment refusal seems irrational" (Kontos *et al.*, 2013, p. 105). Conversely, blindly accepting the plurality of values without challenging those contrary to the individual's

stated interests could be considered neglectful (Kontos *et al.*, 2013). Consequently, Kontos and colleagues (2013) argue that an explicit values component reveals instances where questions of capacity stem from differences in values while allowing inconsistency to be challenged (Freyenhagen & O'Shea, 2013; Kontos *et al.*, 2013).

Past, present or future selves? So far discussion has identified how people could be deemed to lack capacity based on questions about the 'authenticity' of their decisions. Thus, assessment (loosely) relies on identifying a 'past competent self' and comparing current decision-making with this self, privileging past selves at the expense of current selves. Conversely, the MacCAT requires consideration of the consequences of a decision, implying an ability to consider future selves (Appelbaum & Grisso, 1995; Grisso & Appelbaum, 1998; Grisso *et al.*, 1997, 1995). Yet people are constantly changing and evolving; one's 'self' is rarely fixed. This leads to two dilemmas; first how can capacity assessment acknowledge the plurality and changing nature of a person's 'self', and second, does this dynamism undermine the MacCAT requirement to consider future selves?

Consider, John, a person with bipolar affective disorder, and how his decisions might change in a manic phase. Now consider Jane, an academic who has always vowed she would never want to live with a cognitive impairment and signed an advance directive to this effect, yet who, on developing advance-stage dementia, lives a simple, but apparently happy, life. Finally, consider Alice, a person with anorexia, who cannot conceive of an identity not involving her illness. Can the same approach be used for each of these people?

Three approaches seek to reconcile the tension between past, present and future selves. A 'liberal' view maintains that past selves must be respected, even if contradicting current selves (Craigie, 2013; Donnelly, 2009). In contrast, a 'longitudinal' view argues that "people experiencing various life events . . . may revise their goals, values and definitions of personal wellbeing" (Donnelly, 2009), and consequently present (and potentially future) selves should be prioritised. Finally, Buchanan and Brock (1989) reconcile these views using the concept of 'psychological continuity' – "the connectedness of psychological features . . . across a lifetime" (Parfit, 1983 & 1984, cited

in Craigie, 2013, p. 9). They suggest the weight given to past or present selves should reflect the continuity "between the prior capable patient and the current incapable one" (p.26). Applying these approaches to the case studies above highlights difficulties inherent in each approach.

In the case of John, psychological continuity is significantly broken but is expected to be regained. Consequently *past* selves should be used to measure decision-making capacity. This fits with the often transient impact of mental illness on a person's sense of self.

Yet where would this leave Jane, the cognitively impaired academic? How would we weigh her previously held preference to die if faced with these circumstances? In this case, while psychological continuity is dramatically broken, it is not expected to be regained. Instead, according to a longitudinal view, a new self has been created and capacity should therefore be assessed in accordance with this *current* self.

What about Alice, the woman with anorexia? Many people with anorexia describe their identity as inextricably tied to their diagnosis (Freyenhagen & O'Shea, 2013; Garrison, 2007; Hope *et al.*, 2011; Tan *et al.*, 2003), with some struggling to distinguish between their authentic and their anorexic selves (Tan *et al.*, 2003). The argument for a distinct break in psychological continuity is therefore weak – change may be gradual and there may be little hope for the 'past self' to be regained. Instead, the process of value formation could fit with a longitudinal view of identity development, entailing an assessment of authenticity based on *current selves*. Yet many feel hesitant to do so.

This hesitancy could be tied to Alice's failure to consider future selves. Under a cognitive assessment model, a person must be able to evaluate the consequences of a decision, with failure to do so indicative of incapacity (Craigie, 2013). Yet Craigie (2013) questions the validity of this requirement, stating that a person may not hold the same values in the future and therefore not giving consideration to your future self is only relevant to the extent you *are* your future self. In other words, while the ability to consider one's future self may be useful in denying Alice decision-making capacity, could we comfortably accept Jane's advance directive as based on a true understanding of her future (incapacitated) self?

Incapacity thresholds – Risk-relative or decision-specific? The final debate refers to the threshold at which person is deemed to lack capacity, with some proposing it should be risk-relative while others argue it should be decision-specific (Berghmans, 2001).

According to advocates of the risk-relative approach, the *outcome* of the decision is relevant to capacity assessment (Brock, 1991; Buchanan & Brock, 1989; Oliver, 1997; Wilks, 1997, 1999). This outcome-oriented (Wicclair, 1991a, 1991b), externalist position asks 'what level of capacity is required for this *choice'* (Berghmans, 2001; Buller, 2001)? Advocates for this stance often argue for a sliding scale of capacity, with a low threshold where decisions are low risk, increasing commensurately as the risks or irreversibility of the decision increase (Brock, 1991; Buchanan & Brock, 1989; Oliver, 1997; Wilks, 1997, 1999). They consider it to best balance patient autonomy with beneficence (Brock, 1991; Buchanan & Brock, 1989) and to be efficient, allowing interventions agreed to by an incompetent individual to commence where an otherwise lengthy capacity assessment would order the same treatment regardless (Garrison, 2007).

In contrast, advocates of the decision-specific approach believe thresholds should be based on the complexity of the decision (Berghmans, 2001; Buller, 2001; Cale, 1999; Coverdale, 1996; Wicclair, 1991a, 1991b). This task-based, process-oriented, internalist approach asks 'what level of capacities are needed in order to make this decision' (Berghmans, 2001; Buller, 2001; Wicclair, 1991a, 1991b)? Advocates for a decision-specific approach maintain that risk-relative thresholds result in an asymmetric model of capacity; allowing a person to choose *for* a treatment, but asserting lack of capacity should they choose *against* (Berghmans, 2001; Cale, 1999; Coverdale, 1996; Skegg, 2011; Wicclair, 1991a, 1991b). Thus, when the *question* remains the same but the outcome of one *choice* is more 'risky' than another, "insofar as a choice between these options requires *an ability to comprehend and weigh the consequences of both*, it seems odd to maintain that accepting treatment calls for significantly less decision-making ability than refusing treatment" (Wicclair, 1991b, pp. 103–4 emphasis added). They argue this asymmetry undermines a person's right to decide, implicitly signalling 'we will overrule you if you do not agree with us' (Berghmans, 2001; Cale, 1999).

By and large a risk-relative approach has been taken in practice, as advocated in the New Zealand Family Physician Journal (Perkins, 2002) and in Bell and Brookbanks' (2005) overview of New Zealand mental health law. However, it is unclear whether this is the approach preferred by people with mental illness.

1.1.3 Summary

Summarising the above discussion regarding capacity, a few conclusions can be drawn.

- Capacity is now accepted to be variable and decision-specific.
- Cognitive models assess capacity on four dimensions; communication, understanding, reasoning and appreciation.
- A diagnosis of mental illness no longer automatically denotes incapacity.
- Debates about capacity assessment centre on three main topics:
    - Whether capacity assessment should consider factors undermining decisional authenticity, such as emotionality, altered beliefs or distorted values.
    - Whether capacity should be pegged to past, present or future selves.
    - Whether thresholds for incapacity should be risk-relative or decision-specific.
- People with mental illness have been largely excluded from these debates on capacity assessment.

1.2 Intervening in Times of Diminished Capacity

As views of capacity and mental illness have changed, so too have interventions for individuals experiencing diminished capacity. This section looks briefly at the historical context before exploring the ethical frameworks underpinning decision-

making with, or for, someone with diminished capacity. Four decision-making models are briefly described and aligned with these ethical frameworks and debates on the nature of incapacity. This lays the groundwork for Part 1.3, examining current New Zealand legislation.

1.2.1 Historical Development

Just as understandings of incapacity have developed in accordance with social and cultural changes so, too, have approaches guiding decision-making for, or with, people with diminished capacity.

The early 'status' approach combined with the traditional paternalistic stance of 'doctor knows best' (Atkin, 1997; Bell & Brookbanks, 2005; Brock & Wartman, 1990; Carney, 2012; Coverdale, 1996), meant large groups of people, such as the mentally ill, were stripped of their decision-making rights by virtue of their diagnosis and allotted a surrogate – often a state-appointee – with wide-reaching powers to make decisions for them (Atkin, 2011; Carney, 2012; Wareham, McCallin, & Diesfeld, 2005). Little emphasis was placed on participation of the individual and no distinction was made as to whether incapacity was chronic or variable, total or partial (Atkin, 2011; Carney, 2012; Coverdale, 1996).

However, throughout the 1970s and 80s social movements began to advocate for greater recognition for the rights of those with diminished capacity (Atkin, 1997; Carney & Tait, 1998; Court, 1996; Mental Health Commission, 2002). The deinstitutionalisation movement gathered steam (Carney & Tait, 1998; Court, 1996; Mental Health Commission, 2002; Ministry of Social Development, 2011) stimulating a focus on community integration and 'normalisation' (Carney, 2012; Court, 1996). Models such as the Social Model of Disability, which acknowledges the role of society in 'disabling' citizens (Hansen, 2005), gained predominance, promoting inclusion, rejecting dependence, and entitling everyone, regardless of ability, to citizens' rights (Carney, 2012; Court, 1996; Mental Health Commission, 2002; Ministry of Social Development, 2011). Significant social and economic upheaval in the 1980s and 90s emphasised the free individual as a consumer of health services (Atkin, 1997; Mental Health Commission, 2002; Wareham *et al.*, 2005), precipitating a shift in power and requiring

medical practitioners to consult with patients (now called consumers or service users) (Wareham *et al.*, 2005).

Concurrently, the practice of enshrining generalised statements of human rights into international and national legislation became increasingly popular (Bell & Brookbanks, 2005; Court, 1996; Ministry of Justice, n.d.; New Zealand Law Commission, 2002). One of the most important of these has been the 1966 International Covenant on Civil and Political Rights (ICCPR) (Bell & Brookbanks, 2005), which includes the rights to "self-determination" (ICCPR, 1966, Art. 1), to "liberty and security of person" (ICCPR, 1966, Art. 9), and to be "equal before the law . . . and entitled . . . to the equal protection of the law" (ICCPR, 1966, Art. 26). More recently, the 2006 United Nations Convention on the Rights of People with Disabilities (CRPD), introduced the notion of supported decision-making (Carney, 2012; Donnelly, 2009; United Nations, 2007; CRPD, 2006).

Models of decision-making similarly began to shift from a paternalistic framework where a state-appointed surrogate made decisions *for* the incapacitated person to a "genuine respect for individual autonomy and due process" (Carney & Tait, 1998, p. 148). Greater emphasis was placed on individual autonomy and informed consent, individuals were granted the right to refuse treatment (Bell & Brookbanks, 2005; Skegg, 2011) and health practitioners came under increasing pressure to justify any subversion of individual autonomy (Bell & Brookbanks, 2005; Ryan, 2011). Emphasis shifted to working collaboratively with consumers and maximising their participation in decision-making (Court, 1996; Mental Health Commission, 2002; *CRPD*, 2006; Wand & Chiarella, 2006). Most recently, the Bournewood case in the United Kingdom led to the requirement for safeguards to protect a person of diminished capacity *even when* the individual ostensibly agrees with medical decisions (Nys *et al.*, 2004; O'Brien, 2010).

1.2.2 Philosophies Underpinning Intervention

In light of these social, political and economic changes a range of interventions have been used to meet the decision-making needs of people with diminished capacity (Atkin, 2011; Carney, 2012; Oliver, 1997). Atkin (2011) has positioned these

approaches on a spectrum between 'best interests' and 'individual wishes;' alternatively conceptualised as a tension between the ethical principles of beneficence and autonomy.

Best interests, beneficence and paternalism. At one end of the spectrum is a philosophy emphasising decisions based on the individual's 'best interests' (Atkin, 2011). This stance is underpinned by the ethical principle of beneficence and its exhortation to promote the welfare of patients (Beauchamp & Childress, 2009; DuBois, 2008).

Best interests judgements involve balancing the net benefits and risks of a decision and determining a course of action (Atkin, 2011; Buchanan & Brock, 1989; Dresser, 1993). They often involve value judgements relating to the individual's perceived quality of life (Buchanan & Brock, 1989; Dresser, 1993) and require "an omniscient decision-maker operating against a backdrop of undisputed (although unspoken) values against which the *best interests* of the person lacking capacity can be measured" (Donnelly, 2009, p. 28). Dresser (1993) criticises these normative judgements, suggesting they more closely reflect the desires, values and interests of the decision-maker than of the incapacitated individual.

Best interests judgements are often frowned upon because of their association with paternalism. However, some distinguish between strong and weak paternalism (Beauchamp & Childress, 2009; Berghmans, 2001; DuBois, 2008; Sjöstrand *et al.*, 2013). Strong paternalism is often invoked when people discuss the 'evils' of paternalism, where the values of the decision-maker are imposed on the individual irrespective of the individual's capacity or whether he or she holds similar values (Beauchamp & Childress, 2009; Berghmans, 2001; Sjöstrand *et al.*, 2013). In contrast, weak, or soft, paternalism allows an individual's current or past wishes to be overridden only to prevent non-autonomous actions (Beauchamp & Childress, 2009; Berghmans, 2001; Pellegrino, 1994; Sjöstrand *et al.*, 2013). This approach could also justify interventions to restore or promote a person's future autonomy (Beauchamp & Childress, 2009; Sjöstrand, 2013; Sjöstrand *et al.*, 2013; Sjöstrand & Helgesson, 2008). However, weak paternalism is frowned upon by others as tokenism, giving people the illusion of choice but ultimately sanctioning its veto (Dresser, 1993; Mental Health Commission, 2002).

Individual wishes and autonomy. At the other end of the spectrum is an approach prioritising the individual's '*wishes,'* or autonomy (Atkin, 2011). It is based on the idea of human agency as inviolate, with individuals best positioned to know their own 'best interests' (Beauchamp & Childress, 2009; Dworkin, 1993; Mill, 1859; Pellegrino, 1994); consequently, a wishes approach maximises self-determination (Court, 1996).

Interventions prioritising the individual's wishes take as a starting point a presumption of competence and respect for the individual (Atkin, 2011; Carney & Tait, 1998; Mental Health Commission, 2002). They recognise the often transient and decision-specific nature of incapacity and endeavour to either facilitate the person's own decision-making or promote decision-making based on the individual's views when competent (Atkin, 2011; Court, 1996).

However, 'wishes' models are often undermined by the subtle inclusion of elements of paternalism. For example, Pellegrino (1994) comments that while autonomous models are often positioned as antithetical to paternalism, in compelling a 'positive' obligation "to foster the capacity of self-determination" (p.49) they could, in theory, advocate paternalistic, invasive intervention against someone's wishes (such as electroconvulsive therapy) in the name of restoring autonomy.

A second issue asks to what extent should a wishes paradigm should privilege a person's *past* autonomy over his *current* autonomy (Craigie, 2013; Donnelly, 2009; Dworkin, 1993; Sjöstrand, 2013)? This relates to previous discussions about whether past, present or future selves should be privileged and whether a person can realistically plan for a future of which one has no experience (Buchanan & Brock, 1989; Craigie, 2013; Dworkin, 1993; Pellegrino, 1994; Sjöstrand & Helgesson, 2008).

Two approaches have been suggested to resolve this. Dworkin (1993) suggests decision-making should focus on a person's "integrity" – the capacity of the individual "to express one's character – values, commitments convictions" (p.224) and to make "a judgement about the overall shape of the kind of life he wants to have led" (p.226) – despite any inability to foresee certain circumstances. Although not explicitly stated, this seems to be tied to the idea of psychological continuity and suggests the inclusion of a values component with the view that if current, incapacitated, wishes are consistent

with the general character of the individual's life, these should be respected. A second approach would have the decision-maker honour the decision with the least negative consequences and irrevocability (Kohn, Blumenthal, & Campbell, 2012; Wilks, 1999). However this would again sanction the inclusion of a 'best interests' judgement into decision-making.

Finally, although proxies are often instructed to make decisions based on 'what John would have wanted,' people do not "always lead structured, reflective lives" (Dworkin, 1993, p. 224) and it is often difficult to assess what decision the individual would have made (Bailey, 2002; Buchanan & Brock, 1989; Donnelly, 2009; Dresser, 1993; Jenkins & Williamson, 2012; Lowy, 1988). Consequently, past "remote and impersonal" statements are often used as the basis for decision-making, with decisions frequently reflecting the "values, needs and interests of the people who [remain]" (Dresser, 1993, pp. 619, 620; Buchanan & Brock, 1989; Donnelly, 2009).

1.2.3 Models of Decision-Making

Between wishes versus interests, a number of models provide frameworks for decision-making for, on behalf of, or with, the individual with diminished capacity. These models, although overlapping significantly, can be divided into four categories; surrogate decision-making, substituted judgement, advance directives and supported decision-making. These are discussed briefly, placed on the continuum of 'best interests' versus 'wishes,' and linked to the debates relating to the assessment and definition of mental capacity.

Surrogate decision-making. *Surrogate* or *substitute decision-making* refers to the appointment of someone to make decisions *for* another (Gooding, 2013; Kohn *et al.*, 2012; O'Brien, 2010). As it is generally applied, surrogate decision-making refers to those models where there is no direct reference to the individual's wishes, or, where such references are made, they are tempered by requirements such as those to consider the individual's welfare "first and paramount" (PPPR Act, 1988, sec. 18(3)).

Surrogate decision-making according to this definition refers to the (generally) paternalistic exercise of the state's power with little or no input by the individual (Buchanan & Brock, 1989) in an attempt to secure the individual's 'best interests' and

"provide against abuse and exploitation by others, or potentially harmful actions by the individual themselves" (Gooding, 2013, p. 434). Although sold as a method of 'last resort,' Kohn *et al.* (2012) comments that processes for guardianship, especially in cases of intellectual disability, are often streamlined, indicating the continued influence of a 'status' approach.

Considering the debates on capacity, surrogate decision-making is based on a notion of 'global incompetence.' It sets a high, risk-relative threshold for capacity that includes elements of authenticity such as emotionality, beliefs or distorted values, and sits on the 'best interests' end of the spectrum, prioritising 'future selves.'

Substituted judgement. *Substituted judgement* refers to decision-making *on behalf of* a person with mental illness. Like surrogate decision-making, it often involves the appointment of a proxy, however this proxy is enjoined to find out "how [the incapacitated individual] would choose if competent, and then act in accordance" (Lowy, 1988, pp. 15–6; Atkin, 2011; Bailey, 2002; Buchanan & Brock, 1989; Court, 1996; Donnelly, 2009; Wand & Chiarella, 2006). Ideally, the person making the substituted judgement has a close association with the person and a detailed understanding of his or her wishes (Bailey, 2002; Sjöstrand & Helgesson, 2008), and for this reason family are often the first to be considered (Bailey, 2002; Donnelly, 2009; Lowy, 1988).

Substituted judgement is considered to respect self-determination and integrity (Atkin, 2011; Bailey, 2002; Buchanan & Brock, 1989; Court, 1996; Lowy, 1988; Torke *et al.*, 2008). However, in the absence of specific evidence of a person's preferences, substituted judgement decisions can often be based on normative "generalizations [*sic*] about what most people would want" (Lowy, 1988, p. 17; Buchanan & Brock, 1989; Donnelly, 2009; Dresser, 1993). This denies those forms of life not conforming to a mainstream (competent) world view, inserting a degree of beneficence into decisions.

The extent to which the now-incapacitated person is the same as the previous, competent individual poses another difficulty (Bailey, 2002; Buchanan & Brock, 1989; Lowy, 1988; Torke *et al.*, 2008). Rather than promoting autonomy, a substituted judgement model could deny the incapacitated individual the right to self-determination; the decision-maker is required to consider the beliefs and values of the

individual "only as they were up until the time that the individual became incapacitated. The incompetent individual has no opportunity to revise previously held desires" (Bailey, 2002, p. 486; Lowy, 1988). This ties to questions of psychological continuity and whether to privilege past, present or future selves.

Finally, concern is expressed about the inclusion of personally-involved others in decision-making on behalf of the incapacitated individual (Bailey, 2002; Buchanan & Brock, 1989; Sjöstrand & Helgesson, 2008). On the one hand this is seen as necessary and beneficial; those closely connected to the now incapacitated individual are often best placed to determine prior wishes (Bailey, 2002; Sjöstrand & Helgesson, 2008). However, because professionals have little knowledge of the individual's "value history," they are unable to verify accounts given by decision-makers, opening substituted judgement models to abuse (Bailey, 2002; Buchanan & Brock, 1989; Sjöstrand & Helgesson, 2008).

Substituted judgement models ostensibly view capacity as cognitive and decision-specific, although the exclusion of the individual from decision-making could suggest undercurrents of 'global incompetence.' It sits towards the 'wishes' end of the spectrum, privileging past selves, although there is potential for best interests judgements to influence decisions.

Advance directives. At the extreme end of protecting autonomy lie *advance directives*, which allow individuals to dictate in advance what should happen should they lack capacity (Buchanan & Brock, 1989; Carney, 2012; Clausen, 2014). An advance directive can be instructional, directly specifying one's wishes, or it can involve the nomination of a proxy (Buchanan & Brock, 1989). Advance directives are considered to safeguard a person's right to self-determination (Brudney, 2009; Buchanan & Brock, 1989) and in mental health are lauded for promoting consumer involvement in recovery planning (Buchanan & Brock, 1989; Clausen, 2014).

However, while advance directives most closely reflect a person's wishes and preserve his or her (past) autonomy (Dworkin, 1993), there are scenarios where the application of an advance directive can be problematic; What if the advance directive is contrary to the individual's current welfare (Buchanan & Brock, 1989; Dresser, 1993)?

What if the now-incapacitated self disagrees with the past-competent self (Dresser, 1993; Pellegrino, 1994)? And, to what extent could the person making the advance directive have foreseen the current circumstances (Buchanan & Brock, 1989; Pellegrino, 1994)?

All point to the dilemma between privileging past versus current or future selves: To what extent is the current incapacitated individual the same as the past, competent individual, and therefore to what extent does the advance directive apply to this new self? To what extent can people foresee the reactions of their 'future selves' to future circumstances, including their emotional responses (Buchanan & Brock, 1989; Dresser, 1993; Pellegrino, 1994)?

Furthermore, although presented by some as a form of supported decision-making (Bell & Brookbanks, 2005; Davidson *et al.*, 2015; Kohn *et al.*, 2012), advance directives could be considered to completely remove the incapacitated individual from decision-making, undermining current (compromised) selves.

Thus, while advance directives privilege individual wishes, even so far as allowing the individual to pre-emptively stipulate a preferred capacity assessment model and thresholds for incapacity, they clearly privilege past selves to the exclusion of others.

A new paradigm: Supported decision-making. *Supported decision-making* (SDM) is a model where, rather than transferring the powers of decision-making to another, the individual is supported in decision-making with "the presumption . . . in favour of the person with a disability who will be affected by the decision. The individual is the decision-maker" (United Nations, 2007, p. 89; Carney, 2012; Gooding, 2013; Jenkins & Williamson, 2012; Kohn *et al.*, 2012; Pathare & Shields, 2012).

SDM is a central component of the 2006 United Nations Convention on the Rights of People with Disabilities (CRPD), which requires signatories to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (CRPD, 2006, sec. 12). In the United Nations' *Handbook for Parliamentarians*, this is explained more fully:

> Supported decision-making can take many forms. Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity.
>
> (United Nations, 2007, pp. 90–1)

Arguments for SDM fall into two categories. The civil rights argument contends that SDM is best placed to protect and enhance an individual's autonomy (Gooding, 2013; Kohn *et al.*, 2012; Pathare & Shields, 2012). It is in keeping with the social model of disability, which considers capacity to be impaired by society's inability to scaffold the decision-making of less capable citizens (Kohn *et al.*, 2012) and is in accordance with international law (Donnelly, 2009).

Others advocate for SDM from a best practice perspective (Donnelly, 2009; Kohn *et al.*, 2012). Involvement in decision-making is a core element of recovery (Mental Health Commission, 2002), allowing individuals to practise decision-making skills and empowering them through increased self-determination, self-esteem, and self-confidence (Davidson *et al.*, 2015; Kohn *et al.*, 2012; Pathare & Shields, 2012). SDM is also believed to facilitate better decision-making (Donnelly, 2009) while reducing the 'burden' of responsibility on support people (Davidson *et al.*, 2015).

SDM acknowledges the need for different levels of support depending on the individual, the decision, and the context (Gooding, 2013). Referring to the debates on capacity, SDM sees capacity as decision-specific, privileges the person's current self and prefers a 'limited' circumscription of capacity as seen in cognitive models. However SDM does come up against a "potentially unavoidable paradox in acknowledging that a person has diminished decision-making capacity but maintaining that he or she is nevertheless capable of meaningfully contributing to decision-making discussions and that the decisions that result from such discussions reflect his or her wishes" (Kohn *et al.*, 2012, p. 1140). This hearkens back to the idea of authenticity, suggesting that although a cognitive model of capacity may be preferred, elements of 'authenticity' may intrude.

1.2.4 Summary

These four models of decision-making, their underlying philosophies, their views of capacity, (including their likely views on current debates) and their empowerment patterns are summarised in Table 1 (overleaf).

Table 1.

Models of Capacity and Underlying Philosophies, Views on Capacity and Empowerment Patterns.

	Surrogate decision-making	Substituted judgement	Advance directives	Supported decision-making
Underlying philosophy	Best interests	Wishes, can have elements of best interests	Wishes	Wishes
Model of capacity	Global incompetence	Rhetoric refers to presumption of competence, application suggests global incompetence	Stipulated by individual	Presumption of competence Decision-specific.
Decision-making powers granted to others	Far reaching powers granted	Broad application once deemed incompetent	As delineated by individual	Decision-specific
Position on current debates				
- Cognitive capacity vs. authenticity	High standard of autonomy required for capacity	Rhetoric suggests cognitive model	Capacity model determined by advance directive	Cognitive capacity
- Past, present or future selves	Ability to consider future self	Past selves/wishes	Past selves/wishes	Present selves (future considered to the extent that the individual wishes to do so)
- Risk-relative or decision-specific	Risk-relative threshold	Decision-specific threshold	Threshold set in advance directive	Decision-specific threshold
Who is empowered?	Strong state involvement to provide control, care. Often exercised through medical practitioners	Nominated proxy (usually family). Ostensibly incapacitated individual, however may only be past, competent self	Past, competent self	Individual with diminished capacity

1.3 New Zealand Legislative Approaches

> The law necessarily reflects the views and values of the country and the times in which it is enacted.
>
> (Carney, 2012, p. 4)

So how do these frameworks apply to New Zealand legislation relating to the assessment and management of people with mental illness and diminished capacity? This section briefly describes key New Zealand legislation pertaining to people with mental illness and diminished capacity before identifying inconsistencies related to contemporary debates on capacity.

1.3.1 Current New Zealand Legislation

In New Zealand, three pieces of legislation have specific relevance to people with diminished capacity and mental illness:

The 1988 Protection of Personal and Property Rights Act [the PPPR Act] is the "principal statutory vehicle for providing adult guardianship" (Atkin, 1997, p. 77). It allows for three kinds of orders in respect of the person with diminished capacity; Personal Orders (including appointment of a welfare guardian), Property Orders (including appointment of a property manager) and Enduring Powers of Attorney (EPOA). It is based on two principles:

1. A presumption of competence, including a recognition that unwise decisions are not grounds for a judgement of incapacity, and
2. An emphasis on the least restrictive intervention and a duty to encourage individuals to develop and exercise capacity.

(*PPPR Act*, 1988)

The 1993 Health and Disability Commissioner Act [the H&DC Act] and its subsequent Code of Health and Disability Services Consumers' Rights (the H&DC Code)

sets out ten rights of persons receiving health and disability services (Health and Disability Commission, 2009). These include rights to respect (Right 1), freedom from discrimination, coercion, harassment and exploitation (Right 2), dignity and independence (Right 3), and full disclosure and informed consent (Rights 6 and 7) (Health and Disability Commission, 2009). Of particular importance, Right seven sets out a hierarchical decision-making procedure for when capacity is diminished and introduces the right to an advance directive (Health and Disability Commission, 2009).

The 1992 Mental Health (Compulsory Assessment and Treatment) Act [the (MH(CAT) Act], allows a person to be detained and treated against his or her will provided there are "reasonable grounds" to believe that person is "mentally disordered" to such a degree it;

- Poses a serious danger to the health or safety of that person or of others, or
- Seriously diminishes the capacity of that person to take care of himself or herself.

(*MH(CAT) Act*, 1992, sec. 2(1))

The MH(CAT) Act also allows for Community Treatment Orders, compelling individuals to accept outpatient treatment.

1.3.2 Inconsistencies

Several commentators have noted inherent contradictions between these laws (Atkin, 1997; Bell & Brookbanks, 2005; Butler & McVeagh, 2008; Court, 1996; Oliver, 1997; Wareham *et al.*, 2005). In part, this could be due to fundamental differences in understandings of capacity and underlying principles. Using the framework provided in Table 1, these inconsistencies are briefly considered.

The PPPR Act is underpinned by principles such as the presumption of competence, the right to make an unwise decision, a recognition of 'partial' capacity and the requirement to support the individual to exercise his or her capacity (PPPR Act, 1988). It describes incapacity as an inability to "understand the nature, and foresee the consequences of decisions and to communicate these decisions" (PPPR Act, 1988, sec. 5). Thus it appears to utilise a decision-specific, cognitive model of capacity assessment,

with decision-making based on the individual's contemporaneous wishes by utilising a form of supported decision-making (Bray, Dawson, & Van Winden, 2000; PPPR Act, 1988). However, Carney (2012) argues the requirement for an individual to "wholly" lack capacity before a welfare guardian can be appointed tends toward a notion of 'global incompetence,' while the requirement for the appointee to act in the individual's "best interests" (PPPR Act, 1988), implies a paternalistic decision-making model. Furthermore, Bray *et al.* (2000, p. 24) note that the court's role as final arbitrator and protector of "vulnerable people" suggests a paternalistic, 'best interests' stance.

Like the PPPR Act, the H&DC Code also stresses a presumption of competence (Health and Disability Commission, 2009, sec. 7(2)), suggesting a decision-specific model of capacity endorsing respect for an individuals' wishes. It offers a hierarchical 'menu' of decision-making models, preferring in the first instance the informed consent of individuals to the level of their ability (autonomous/supported decision-making), next seeking consent from a legal surrogate, and finally a "best interests" decision incorporating substituted judgement through the requirement to ascertain whether the decision is "consistent with the informed choice the consumer would have made if he or she were competent" (Health and Disability Commission, 2009, sec. 7(4)). It provides for the recognition of advance directives; however as these are not legally binding (McKenna *et al.*, 2007) it is unclear how this balances with the requirement for a "best interests" decision. This hierarchy of decision-making privileges individual autonomy, potentially at the expense of family or collective interests (Court, 1996), something discussed further in Part 1.4.

In contrast to the PPPR Act and the H&DC Code, there is little reference to capacity in the MH(CAT) Act (Bell & Brookbanks, 2005; Butler & McVeagh, 2008; Court, 1996; Oliver, 1997); a person can be detained when capacity is retained provided he or she is "mentally disordered" and poses a "serious danger to . . . that person or [to] others" (MH(CAT) Act, 1992, sec. 2(1)). Furthermore, while the MH(CAT) Act requires the responsible clinician to seek informed consent to treatment, a competent refusal can be overridden provided the treatment is in a person's best interests (MH(CAT) Act, 1992, sec. 59). Consequently, some writers (Atkin, 2011; Bell & Brookbanks, 2005; Court, 1996; McKenna *et al.*, 2007; O'Brien, 2010) suggest the MH(CAT) Act continues to apply a notion of 'global incompetence,' with a person deemed to lack capacity by virtue

of involuntary admission. The MH(CAT) Act privileges the individual's "best interests" (Atkin, 1997; McKenna *et al.*, 2007; O'Brien, 2010), utilising a surrogate decision-making model (Court, 1996; O'Brien, 2010) which, although imposing a duty to consult with family/whānau (MH(CAT) Act, 1992, sec. 7A), does not mandate family involvement in decision-making (Ministry of Health, 2006). The implication seems to be that the MH(CAT) Act promotes a model of "medical determination" (Atkin, 1997, p. 95), where "any treatment that may seem to clinicians to be desirable may be administered irrespective of the wishes of the patient or his or her family" (Brookbanks, 1994, p.190, in Court, 1996, p.14).

1.3.3 Summary

New Zealand laws have fundamentally different approaches to incapacity which reflect disparities in perceptions of capacity and philosophies underlying intervention. Accordingly, decision-making interventions for those with diminished capacity vary. These differences are summarised in Table 2 (opposite).

Table 2.

Differences in Approach Between New Zealand Laws Applicable to People with Mental Illness Who Lack Capacity

	PPPR Act	H&DC Act (Advance directives)	MH(CAT) Act
View of capacity	Decision-specific, but with elements of global incapacity.	Decision-specific.	Presumption of global incapacity based on involuntary admission.
Decision-making model	Supported decision-making, but with undercurrents of substituted judgement and surrogate decision-making.	Right 7 implies hierarchy of supported decision-making, surrogate decision-making and substituted judgement. Allows for advance directives.	Surrogate decision-making.
Wishes versus interests	Wishes, with undercurrents of interests.	Wishes. Best interests decision only in certain circumstances.	Best interests.
Position on current debates			
- Cognitive capacity vs. authenticity	Utilises cognitive model of assessment.	No explicit model delineated.	No capacity assessment required.
- Past, present or future selves	Emphasis on maximising participation suggests present selves, however "best interests" principle indicates future selves.	Advance directive/substituted judgement privileges past selves. Requirement to consult with individual indicates present selves.	Best interests decision indicates future selves.
- Risk-relative or decision-specific	"Best interests' principle suggests risk-relative.	Not stated.	"Dangerousness" criteria suggests risk-relative.
Who is empowered	Individual through requirement to maximise capacity. Nominated individual (often family). Courts.	Individual's past wishes. Some reference to "other suitable persons."	Medical practitioners, courts.

1.4 What About Culture?

> Ehara tāku toa i te toa takitahi, engari he toa takitini
> My strength is not mine alone, it comes from the collective
> (Māori Proverb, Brougham & Reed, 1999, p. 135).

> Ko te whānau ko hau, ko hau ko te whānau
> I am the whānau and the whānau is me
> (Moeke-Pickering, 1997, p. 18)

The shift in ethical, legislative and policy imperatives towards autonomy described above has been a fairly recent, Western, phenomenon (Blackhall *et al.*, 1995; Dresser, 1993; Freyenhagen & O'Shea, 2013; Hanssen, 2004; Levine, 1991; Ruhnke *et al.*, 2000). Consequently, some argue insufficient consideration has been given to the influence of cultural norms on decision-making (Charles, Gafni, Whelan, & O'Brien, 2006; Hanssen, 2004; Markus & Kitayama, 1991; Pellegrino, 1994; Ruhnke *et al.*, 2000; Wand & Chiarella, 2006).

Current models of capacity assessment and intervention in incapacity could be seen as ethnocentric, failing to account for cultural differences in decision-making. For example, a study by Blackhall *et al.* (1995) compared the opinions of Korean-Americans, Mexican-Americans, African-Americans and European-Americans on whether a patient should be advised of a terminal diagnosis and who should make treatment decisions. The study found Korean-Americans were more likely to believe patients should not be told their diagnosis and families should make treatment decisions. A study by Ruhnke and colleagues (2000) comparing the attitudes of Japanese physicians and patients with their American counterparts found similar differences.

Many theories have been posited to explain these differences. These include theories on beliefs about the need for family to "protect" the patient from bad news (Dalla-Vorgia *et al.*, 1992, in Blackhall *et al.*, 1995), cultural differences in deference to hierarchy (Hanssen, 2004), learned responses informed by discrimination, differences in

world views relating to health and wellbeing, and differences in health literacy (Patel & Bakken, 2010). However, by far the most oft-cited explanation is the difference between Western, individualistic, independent cultures (Markus & Kitayama, 1991) and collectivist, family-centred (Blackhall *et al.*, 1995; Bujo, 2005; Ujewe, 2012), interdependent (Markus & Kitayama, 1991) cultures.

In individualistic societies, members are encouraged to develop an independent self, "detached from context," with actions and behaviour arising from one's own internal, coherent set of values, beliefs and attitudes (Markus & Kitayama, 1991, p. 225; Hanssen, 2004). Asserting oneself is seen as appropriate and desired, typified by the aphorism "the squeaky wheel gets the grease." This independent self is privileged by the cultural emphasis on individual autonomy.

In contrast, collectivist societies tend to emphasise group solidarity (Hanssen, 2004) and an "interdependent" self (Markus & Kitayama, 1991). Interdependent societies see the self as part of a greater whole, with actions arising from social context rather than individual desires, feelings or thoughts (Markus & Kitayama, 1991). In fact, in Japan, "the straightforward claim of the naked ego is experienced as childish . . . immature" (Hanssen, 2004, p. 33; Markus & Kitayama, 1991). People are motivated by a desire to fit in, and the normative imperative is to maintain one's interconnectedness and interdependence, typified by the Japanese saying "the nail that sticks out gets pounded down" (Markus & Kitayama, 1991, p. 224).

This difference between independent and interdependent selves could influence decision-making in ways not accounted for by traditional capacity assessment and intervention models. For example, Doi (1986, in Markus & Kitayama, 1991) asserts Americans are "decidedly more concerned with consistency between feelings and actions than are the Japanese" (p.240) and that the requirement for decisions to be motivated by "internal, individually rooted needs or motive[s]" (p.239), may not be as strong for people with interdependent selves, who are accustomed to regulating private emotions. Thus, the current emphasis on coherence between one's values and one's decision may be a Western concept.

Furthermore, the focus on *individual* decision-making may also be culturally bound. Cultures focussing on independent selves treat the involvement of and deferral

to others in decision-making as inherently suspicious (Ho, 2008). Yet in interdependent cultures, this is a normal, natural and supportive part of decision-making (Leever, 2011; Minkoff, 2014). In contrast, the Western focus on individual decision-making can be "isolating and burdensome" (Blackhall *et al.*, 1995, p. 824; Gostin, 1995). This hearkens back to the discussion of relational autonomy in Section 1.1.2, and suggests that decision-making models privileging individual autonomy may not account for natural decision-making processes.

This is relevant to the New Zealand context. New Zealand considers itself a bicultural society, with the Crown obligated to bicultural service delivery and to provide for Māori perspectives and practices (Mental Health Commission, 2002; Wareham *et al.*, 2005). Within the Māori world view the individual is inextricably tied to whānau, hapū, iwi and the environment (Moeke-Pickering, 1997; Wareham *et al.*, 2005), with whānau involvement essential to decision-making (Atkin, 1997; Durie, 1998; Moeke-Pickering, 1997; Wareham *et al.*, 2005). This calls into question the appropriateness of individually-oriented models of capacity and decision-making, such as advance directives or the allowance for only one welfare guardian under the PPPR Act (Atkin, 2011).

Further, while discussion has focussed on independent, 'Western' cultures versus interdependent cultures, individuals within Western societies themselves differ in the extent they value individual autonomy over relational autonomy (Blackhall *et al.*, 1995; Dresser, 1993; Hanssen, 2004). Consequently, acknowledging that capacity, placed within the doctrine of individual autonomy, is a largely Western construct allows us to question 'taken for granted' assumptions about the nature of capacity and the appropriate balancing of individual versus relational autonomy in decision-making. Ironically, by insisting on autonomy in all situations, the medical profession may be reinforcing a paternalistic stance that while people can decide what they want, the 'doctor knows best' when it comes to how they arrive at this decision (Blackhall *et al.*, 1995).

1.5 Service-User Perspectives

> I think when I was unwell the worst aspect of it was in and around that whole thing [losing capacity]. I love the fact that I can run my own life and I had lost that for a period. One of the most disabling factors in and around mental health is the fact of that very issue.
>
> (Participant 4 Amnesty International Ireland, 2009, p. 27)

So far, different models of capacity and approaches to intervention with people with diminished capacity have been discussed. New Zealand legislation has been introduced and found to be inconsistent, and there is a suggestion prevailing models and assumptions may be culturally circumscribed. Yet what are the views of people with mental illness? The following section explores this question.

1.5.1 Views on Capacity

Within the debates regarding the nature of capacity, the voices of those who lack capacity are virtually silent, and studies examining people's perceptions of capacity have focussed primarily on people's *self-assessment* of abilities (Ehrlinger, Johnson, Banner, Dunning, & Kruger, 2008; Kruger & Dunning, 1999; Mabe & West, 1982), rather than factors deemed relevant for capacity assessment.

Only one study looked at the attributes individuals considered relevant for capacity assessment. This qualitative study, conducted by Amnesty International (2009) and republished by McDaid and Delaney (2011), asked eight people with mental illness to comment on proposed mental capacity legislation in Ireland and found that although most participants agreed with a cognitive model of capacity, "a range of physical, environmental and social factors" (Amnesty International Ireland, 2009, p. 33) were also deemed relevant, such as how decisions are presented, the "creation" of incapacity by medications, emotional factors such as fear, and the importance of external validation. Participants felt the "all-or-nothing" approach to capacity did not fit their experience;

even when significantly unwell they felt they retained the ability to make some decisions (McDaid & Delaney, 2011). The researchers insisted these findings, particularly the finding that affirmation of abilities could enhance capacity, provide evidence for a socially constructed model of incapacity (Amnesty International Ireland, 2009; McDaid & Delaney, 2011).

The veritable dearth of research on what individuals with diminished capacity believe should be relevant criteria for assessing capacity is in many ways understandable; people need a degree of capacity to engage in the debates regarding the nature of capacity. However, if we accept mental illness as only *temporarily* influencing capacity, then it could be argued that people with mental illness should be able, when competent, to reflect on what it is like to lack capacity.

1.5.2 Preferences for Participation

That inclusion in decision-making leads to better outcomes is widely accepted, even if the final decision is contrary to the individual's wishes (Donnelly, 2009; Mental Health Commission, 2002). Correspondingly, people, including those with mental illness (Noble & Douglas, 2004), have increasingly sought involvement in medical decision-making since the 1970s (Chewning *et al.*, 2012).

A series of studies have been conducted to ascertain the preferences for involvement in decision-making of people with mental illness. Most of these used quantitative rating scales to assess participant preference, such as the Control Preferences Scale (CPS) or the Autonomy Preference Index (API). These studies have found that while the majority of people with mental illness desire some involvement in decision-making, there is less certainty about their preferred role. For example, one such study administered the CPS to 84 people with serious mental illness and reported that 82 percent preferred a collaborative relationship with their prescriber. Similarly, a study of 122 inpatients with schizophrenia using the API indicated "there is no interest on the patients' part to take over decisional control completely but rather that patients strongly wish to participant in medical decisions on an equal footing" (Hamann, Cohen, Leucht, Busch, & Kissling, 2005, p. 2383). However, other studies variously indicated

that people with mental illness have greater preference for *information* than involvement, or simply want to check decisions are 'right' (Woltmann & Whitley, 2010).

In an endeavour to ascertain why preferred involvement varied, subsequent research has attempted to correlate scores on the API or CPS with demographic, diagnostic, experiential or decisional factors. For example, the study above by Hamann *et al.* (2005) indicated that people who had experience of involuntary treatment showed more interest in participation. Adams, Drake and Wolford (2007) surveyed 30 people with mental illness living in the community using the API and CPS and reported that participants' preference for involvement differed according to the decision to be made; participants preferred a more passive role for decisions regarding psychiatric medication than general medical medication. Using a similar correlational methodology, O'Neal *et al.* (2008) found that people with mental illness preferred a more collaborative role for medical decisions compared to a more autonomous role for psychosocial decisions (such as housing or employment. Patients, whether medical or psychiatric, also differed in their preferred involvement in decision-making according to their educational level, health status, severity of health difficulties (Ende, Kazis, Ash, & Moskowitz, 1989; Vick & Scott, 1998), age (Ende *et al.*, 1989; Hamann *et al.*, 2005; Vick & Scott, 1998), satisfaction with care (Hamann *et al.*, 2011), trust in the medical practitioner (Hamann *et al.*, 2011; Myron, Gillespie, Swift, & Williamson, 2008), and self-perceived decision-making skills (Amnesty International Ireland, 2009; Hamann *et al.*, 2011; McDaid & Delaney, 2011). Diagnosis also seems to play a part, with people with depression and anxiety typically showing preferences for passive roles in decision-making (Stacey *et al.*, 2008) while people with schizophrenia placed higher value on surrogate decision-making (Swartz, Swanson, Van Dorn, Elbogen, & Shumway, 2006).

However, the two tools typically used to assess preference for involvement in decision-making, the CPS (Adams *et al.*, 2007; Mahone, 2008; O'Neal *et al.*, 2008) and API (Adams *et al.*, 2007; Hamann *et al.*, 2011, 2005; O'Neal *et al.*, 2008), have a number of shortfalls:

- Both focus on *current* preferences. Thus research captures two response categories; those of people who are well and want decision-making autonomy, and those who are unwell and who may have different preferences for participation than they would prescribe for themselves when well.

- Where studies do ask people to imagine prospective wishes, scenarios don't explicitly address loss of capacity. Consequently, these studies don't address people's *prospective* preferences for involvement *when capacity is diminished*.
- Furthermore, where studies have asked people to imagine future scenarios, answers are combined in overall results. Failing to separate these results means differences between people's current and prospective wishes for participation are lost.
- Both ask questions about *medical decision-making* and suggest alternatives necessitating the involvement of a doctor or psychiatrist. This fails to detect whether people wish to delegate responsibility to another *not* their doctor.

Only two studies using an alternative research methodology were found, both conducted fairly recently: that by Amnesty International (2009; republished by McDaid & Delaney, 2011), and another by Myron *et al.* (2008). Both studies utilised qualitative interviews to explore the experiences of people with mental illness when decisions were made by others during periods of incapacity (Amnesty International Ireland, 2009; McDaid & Delaney, 2011; Myron *et al.*, 2008). These studies found that while some participants acknowledged that delegating decision-making to another could be necessary or a welcome relief, even if they did not agree at the time (Amnesty International Ireland, 2009; McDaid & Delaney, 2011; Myron *et al.*, 2008), others had negative experiences, with one individual stating "[I felt] like I was an object to be discussed," "like a rag doll being torn around the place" (participant, in Amnesty International Ireland, 2009, p. 28; Myron *et al.*, 2008). Many spoke of feeling unheard, or believing their involvement was only elicited on a tokenistic basis (Myron *et al.*, 2008). Others spoke about withholding views for fear of being a burden or of having services withdrawn should they question decisions (Amnesty International Ireland, 2009; McDaid & Delaney, 2011; Myron *et al.*, 2008). Several spoke about wanting some assistance with decision-making, whether practical help, having someone to talk to, or help with problem-solving, suggesting a valuing of supported decision-making (Amnesty International Ireland, 2009; McDaid & Delaney, 2011; Myron *et al.*, 2008).

This paints a complicated picture of preferences for autonomy and involvement in decision-making, with some preferring an approach where decision-making is wholly abdicated to another, others preferring a supported decision-making approach, and

some desiring a mixed approach (Amnesty International Ireland, 2009; McDaid & Delaney, 2011; Myron *et al.*, 2008; Pathare & Shields, 2012). This has important implications for structuring interventions for times when people have diminished capacity.

1.5.3 Preferences for Involvement of Others

Traditionally, where there has been a need for involvement of others in decision-making, this 'other' has been a medical practitioner acting in the individual's 'best interests'. While the increased focus on individual autonomy has resulted in greater consultation with family (Donnelly, 2009; Roupie *et al.*, 2000), the preferences of people with mental illness for involvement of others is unclear.

For example, while a quantitative study surveying 92 psychiatric inpatients found the majority of those experiencing a short-term psychiatric hospitalisation wanted relatives to be involved to some extent (Perreault, Paquin, Kennedy, Desmarais, & Tardif, 1999), Swartz *et al.* (2006), using a semi-structured, manualised discussion of choices involved in advance care planning concluded that community-based patients with mental illness "placed the highest value on continuity of care by gaining treatment their doctors think is best" (p.73). And while a recent meta-analysis by Kelly, Rid & Wendler (2012) of 14 qualitative articles found that "the vast majority of respondents wanted close family to make decisions for them" (p.886), most of the studies included targeted the elderly or seriously ill, casting doubt on its applicability to people with mental illness.

The type of decision and who is involved could explain some variation in participant responses. For example, the study by Amnesty International (2009) asked participants to indicate who they would prefer to have involved in day-to-day, medical or legal decisions. While participants unanimously preferred that someone trusted and close to them be involved in day-today decisions, when it came to mental health treatment decisions, participants expressed more varied preferences including an advocate, the multidisciplinary mental health team or a legal professional.

Social isolation can also pose significant barriers to involving others. In a review of the evidence for supported decision-making (SDM), Pathare and Shields (2012)

identified social isolation and stigma as a significant barrier; participants often spoke of no one being available despite a desire for support from others. Similarly, a qualitative study by High (1990) of the preferences for family involvement of 71 elderly participants found that social isolation and concerns about being a 'burden' resulted in a greater reliance on friends and doctors as surrogate decision-makers.

Thus, while there is research to suggesting people with mental illness want to share decision-making and involve others, studies on how this should operate and who should be involved paint a complicated picture. This is important, as while in New Zealand involvement of family / whānau is culturally relevant and enshrined in legislation, it is not without shortcomings. Although nominated others can be specifically empowered through the granting of an order under the PPPR Act, generally only one person can be nominated (PPPR Act, 1988, sec. 12(6)). The MH(CAT) Act mandates *consultation*, not family involvement in decision-making (Ministry of Health, 2006), while the H&DC Code privileges individual autonomy, giving little space to collective decision-making (Wareham *et al.*, 2005). Consequently, these models do not address the range of possible preferences of people with mental illness, particularly those identifying strongly as Māori, where decision-making is typically undertaken by the whole whānau (Atkin, 1997, 2011; Wareham et al., 2005).

1.5.4 Summary

In summary, little research appears to have been conducted to look specifically at how people with mental illness believe capacity should be assessed and how decision-making should be undertaken if capacity is diminished. Should capacity assessment be based on a purely cognitive model, or should other, authenticity-undermining, influences be considered? To what extent do people wish to remain involved in decision-making if their capacity has been diminished, who else should be involved, and what role should this person take? Do they want them to privilege wishes or interests? And what decision-making model would they want used? It is these questions this study sought to answer.

1.6 Conclusion and Research Questions

(In)capacity is a social construct, hotly debated and constantly in flux. Accordingly, a range of interventions arise when someone's capacity is diminished, interventions which differ according to their understanding of incapacity and the relative weight given to autonomy versus beneficence. Although these debates impact significantly on the lives of people with diminished capacity through their operationalisation in legislation, there is a dearth of research canvassing the views of the people who are directly affected. This may be due to the perception that the subject population lacks the ability to contribute meaningfully to this debate. However, the work reported here is informed by a stance valuing the insights of people with varied capacity, such as those with mental illness.

The research reported here seeks to give voice to the perceptions of people with mental illness, asking:

- Their views on the debates regarding capacity, specifically;
    - Whether assessment of capacity should consider elements such as emotionality, beliefs and values,
    - Whether assessment of capacity should be pegged to past, present or future selves, and
    - Whether the threshold for capacity should be decision-specific or risk-relative.
- Their preferences for participation in decision-making, including prospective views on participation should their capacity be diminished.
- Their prospective preference for involvement of others in decision-making, specifically;
    - Whom they want involved,
    - What role they would want this person to take,
    - Whether they want this person to focus on their wishes or interests, and whether past, present or future wishes should be emphasised.

Chapter 2: Methodology

2.1 Epistemological Perspective and Rationale

This research was undertaken using a postmodern research paradigm; a subset of what Guba and Lincoln (1994) term "critical theory." Utilising a constructivist ontology, it acknowledges that as certain discourses gain dominance, social constructions become "crystallized" [*sic*] within systems (Guba & Lincoln, 1994, p. 110; Payne, 1997). This approach highlights how understandings of capacity have been constructed within academic and clinical/professional domains, privileging the priorities, beliefs and values of the elite, with tangible implications for people with mental illness.

The researcher's emphasis on social justice focussed attention on the views of one group of people who might be disadvantaged by these social constructions – people with mental illness. However, a social constructivist stance acknowledges that people with mental illness are not a homogenous group and that individuals will have different perspectives; for example, someone with bipolar affective disorder, characterised by discrete episodes of unwellness (American Psychiatric Association, 2013), may have different views from someone with an eating disorder, which is viewed by many as integral to their identity (Tan *et al.*, 2006).

This research departed from traditional critical theory's emphasis on transforming 'false consciousness' and political structures through engagement and confrontation, instead employing the principles of participatory research (Lincoln & Guba, 2003). A participatory approach requires that research gives participants tools and insights while simultaneously producing findings that promote meaningful change (Lincoln & Guba, 2003). Croft and Beresford (1994) identify four elements of participatory social work practice which, when applied to this project, stipulated that

the research: a. aimed to empower people, b. offered participants decision-making and planning control, c. equipped participants with knowledge and skills, and d. ensured systems were receptive to service-user involvement.

2.2 Design, Setting, and Sample

2.2.1 Design

The research utilised a cross-sectional, mixed methods design (Creswell & Plano Clark, 2011). A qualitative approach informed sampling and data collection. Data collection consisted of two distinct phases; qualitative focus groups followed by individual interviews, with the first informing the second. Data were analysed using quantitative and qualitative methods.

This mixed methods design was specifically chosen to allow qualitative and quantitative elements to offset each other's shortcomings; this is addressed in Section 2.5.

Study procedures were approved by the University of Otago Human Research Ethics Committee in July 2014 and subsequently amended in November 2014. The Ngai Tahu Research Consultation Committee provided a review of the study. Access to current clients of the Southern District Health Board was approved by Health Research South, the Southern District Health Board's Research Ethics Committee and locality approval was gained from all other participating organisations (Research approvals located in Appendix A).

2.2.2 Setting

Data collection took place within the boundaries of Dunedin, a coastal city in the South Island of New Zealand, with a population of just over 120,000 people in 2013

(Statistics New Zealand, 2015). In 2013 people of European / Pākehā ethnicity made up 88.3% of the inhabitants, compared to a national average of 74%. Māori are the second largest ethnic group, with 7.7% of the population; this is significantly below the national average of 14.9% (Statistics New Zealand, 2015). Data on mental illness within Dunedin suggest that in 2010 1.54% of people within the city were in receipt of income support due to mental illness (Mental Health and Addiction Planning Project, 2011). This cannot be taken as a true indicator of the rates of mental illness within the community as many people with a diagnosis of mental illness do not receive a benefit.

Nationally, it is estimated that 16.3% of the population have had a diagnosis of a common mental disorder (depression, anxiety and /or bipolar affective disorder) (Ministry of Health, 2013). The rates are somewhat higher for women (20%) than men (13%), while the rates of Māori and non-Māori are comparable (Ministry of Health, 2013). However, of the 3.5% of the population accessing specialist mental health services in 2013 (Ministry of Health, 2014b), men and Māori had higher rates of service use (54.2% men versus 45.8% women; 5533 per 100,000 of Māori, versus 3338 per 100,000 nationally) (Ministry of Health, 2014a).

A household survey conducted in New Zealand in 2003 and 2004 found that anxiety disorders have the highest lifetime prevalence (24.9%), followed by mood disorders (20.2%), substance use disorders (12.3%) and eating disorders (1.7%) (Oakley Browne, Wells, & Scott, 2006). Among mood disorders, the most prevalent is major depressive disorder (lifetime rate of 16.0%); with bipolar affective disorder accounting for a lifetime prevalence of 3.8% (Oakley Browne *et al.*, 2006). However, this survey was unable to comment on the prevalence of psychotic disorders due to difficulties with methodology (Oakley Browne *et al.*, 2006).

2.2.3 Sample

General inclusion / exclusion criteria. Specific sampling criteria differed slightly across phases, however broad inclusion / exclusion criteria stipulated that participants;

- Have a diagnosis of mental illness and/or personality disorder as defined by the DSM-IV,

- Are aged between 16 and 67,
- Reside within the Dunedin city catchment area,
- Are able to give informed consent to research participation, and
- Are not current clients of the researcher.

It was hoped that a minimum of five focus groups of at least four participants would be held and no less than ten individual interviews be conducted.

2.3 Data Collection

2.3.1 Recruitment

Research suggests people with mental illness are reluctant to participate in group research activities, whether due to symptomology, stigma associated with mental illness, or distrust of researchers (Allen, Carpenter, Sheets, Miccio, & Ross, 2003; Rauktis, Feidler, & Wood, 1998). Consequently, researchers frequently have difficulty recruiting participants and the same individuals often participate in many research requests (Rauktis *et al.*, 1998). Accordingly, it was felt that recruiting using pre-existing groups, although not a representative sample, might overcome some barriers to participation. For example, Rauktis *et al.* (1998) suggested that people with serious mental illness often lack social skills and may be withdrawn; therefore the reassurance of seeing familiar faces might facilitate group discussion. Similarly, conducting focus groups on 'safe' territory with the sanction of trusted group facilitators could reduce the distrust traditionally levelled at mental health professionals (Allen *et al.*, 2003).

Within Dunedin, a number of groups are run for people with mental illness. A list of these groups was collated and facilitators contacted to request permission to approach group members and invite their participation. Use of existing group time and facilities for focus groups and individual interviews was negotiated with facilitators.

In total, eight organisations were contacted. Facilitator guidance dictated the best method to approach group members; this involved one of two methods:

1. In the majority of cases (five out of eight), the researcher was invited to attend a group meeting to discuss the research in person, with facilitators indicating the best time to approach the group to maximise participant numbers. This sometimes necessitated more than one visit. Information sheets (Appendix B) were provided and a signup sheet circulated for those interested in participating in either focus group discussion, individual interviews, or both. The facilitator then returned to the group at a pre-arranged time and a focus group was held with those who indicated an interest in participating. In one group, members indicated a desire to engage in focus group discussion immediately and thus there was no delay between recruitment and data collection.
2. In three groups, information about the research was provided to group facilitators who then discussed the research with their members and provided information sheets. The group facilitator gauged interest and collected a list of interested persons to be contacted separately.

Best results were obtained when the researcher spoke directly to the group; of the five approached directly, all agreed to participate in the focus group phase. However, two individuals from the groups who declined to participate in the focus group phase indicated an interest in the interview phase.

Participating organisations included the local District Health Board (DHB), two major non-governmental mental health service providers contracted to the DHB, a major social service provider, and a small, member-run organisation. The groups included daily drop-in vocational / activity centres, a cultural group and a series of psychotherapeutic / psychoeducational groups. Of these groups, three were also open to people with intellectual disabilities. Due to restrictions on attendance at one organisation, a total of three focus groups, each on a different day, were held at one facility. Only one focus group was held at each of the other facilities. In total, seven focus groups were held.

To obtain greatest saturation and ensure depth of analysis, qualitative interviews were completed to investigate certain concepts in greater depth, including areas of variation or outliers. Interview participants were drawn from all members of the host organisations who had indicated willingness to participate in this phase. This included those who were unwilling to participate in the focus group phase, those who had

indicated a willingness to be involved in the focus group phase but who were unavailable on the day, and those who had taken part in a focus group but needed to leave early. Although it had been hoped that purposive sampling could be used to ensure diagnostic representation, a lack of volunteers and access to diagnostic information prior to interviews made this impossible. In total, ten interviews were held.

Total number of focus groups and interviews conducted was guided by the principle of theoretical saturation; that is, sampling continued until no new findings were gleaned and all concepts appeared well-defined (Bryman, 2012).

2.3.2 Demographic Data

In order to describe the sample, all participants were asked to complete a questionnaire providing brief demographic and social information including age, gender, ethnicity, diagnosis and basic information on social support networks. A copy of the questionnaire is available in Appendix C.

2.3.3 Procedure: Focus groups

Focus groups were held between September 2014 and March 2015 at the sites of the host organisations during normal group hours. Groups were generally held in a small side room, with light refreshments provided.

Research began by orienting participants to the purpose and focus of the discussion, obtaining informed consent (Appendix D) and providing assistance to complete the demographic questionnaire. Discussion commenced with a brief overview of current legislation relating to mental capacity and complaint mechanisms. A handout summarising this information was provided (Appendix E). Semi-structured focus group discussion was then encouraged, focusing on the three research questions identified in Section 1.6 (see Appendix F for Focus Group Guide Questions). When themes identified in previous research or focus groups were not raised by participants, attention was drawn to these once natural discussion was exhausted.

To frame discussion, participants were asked to reflect on personal experiences or to consider short case examples:

- When discussing risk-relativity, participants were asked to consider whether 'risky' choices were indicative of diminished capacity in one of two scenarios; either choosing whether to eat dinner (usually a straightforward, low-risk decision) in the case of anorexia (where the risk is considered higher), or choosing to live "on the streets" when there was an option of more "suitable" accommodation.
- When discussing 'unusual' values participants were asked to consider whether value priorities considered 'unusual' by the general public should be considered indicative of diminished capacity. An example given was the potential valuing of 'thinness' over 'life' in the case of anorexia.
- When discussing best interests versus individual wishes, participants were asked to consider a hypothetical scenario of a woman with dementia who wants to remain at home despite her condition placing her at significant risk of harm should she do so.

These case examples facilitated participant understanding by anchoring complex concepts in concrete situations, while a feeling of distance between participants' answers and themselves enabled more sensitive questions to be asked (Finch, 1987, cited in Bryman, 2012). Conversely, this distance could depersonalise the study and vignettes may have limited discussion to that scenario.

After each focus group detailed field notes were taken to capture researcher observations on setting, participants, process, insights, and further questions. Focus group discussion was recorded and transcribed. Preliminary data analysis was undertaken concurrently with further data collection, resulting in an inductive research process, with past focus groups informing future discussions. Audio files of initial focus groups were reviewed by the research supervisor and discussed.

2.3.4 Procedure: Individual Interviews

Individual interviews were held between March and June 2015. Light refreshments were again provided and all interviews were conducted in a side room made available by host organisation staff.

Interviews commenced by orienting participants to the purpose and focus of the discussion, obtaining informed consent, and providing required assistance to complete the demographics questionnaire (those participants who had previously attended a focus group were not required to complete the questionnaire a second time). As with focus groups, participants were provided with a brief overview of current law, before opening the interview for discussion. Although the overarching themes of discussion remained as described above, more attention was paid to the reasoning behind participants' views and themes emerging from focus group discussion. These themes included autonomy versus influence, closer questioning on the role of values, complications associated with involving others, and participant views on advance directives (see Appendix F for Interview Guide Questions).

Field notes were recorded immediately after each interview to capture facilitator observations. Interviews were recorded and transcribed, and as with focus groups, preliminary data analysis was undertaken concurrently with data collection. Initial transcripts were reviewed by the research supervisor and discussed.

2.4 Data Analysis

Focus group and interview data were analysed with regard to the three themes identified above. Data were analysed as follows.

2.4.1 Qualitative Data Analysis

Constant comparison analysis (CCA). CCA is used to identify underlying themes and relationships between ideas and concepts (Krueger & Casey, 2009; Leech & Onwuegbuzie, 2007). Questions related to research topics were asked of the data and transcripts coded into "component parts that seem to be of potential theoretical significance and/or that appear to be particularly salient" (Bryman, 2012, p.568). Codes

were then 'chunked' into larger themes (Leech & Onwuegbuzie, 2007). Emerging themes were further explored by re-examining transcripts and in future focus groups and interviews. Thus, for example, the theme 'involving others' in capacity assessment and decision-making was frequently raised with qualifying statements and provisos; raising questions such as 'what attributes are required of involved others?' and 'what conditions promote positive versus negative involvement of others?' This necessitated reflection on codes developed and identification of emerging themes while being sensitive to contrasts and similarities between them (Bryman, 2012). Divergent opinions were also attended to, as these presented alternate viewpoints for exploration in future focus groups and interviews. Themes were identified and coding sheets matched themes with relevant quotes. These coding sheets were reviewed by the research supervisor who had experience in CCA.

Content analysis (CA). Key themes and categories identified through CCA were quantified using content analysis. Content analysis facilitates the production of quantitative data for statistical analysis (Bryman, 2012; Leech & Onwuegbuzie, 2007). It goes beyond simply counting instances of words or themes, involving a "subjective interpretation of the content of text data through the systematic classification of coding and identifying themes or patterns" (Hsieh, 2005, p. 1278 emphasis added). Hsieh and Shannon (2005) identify three approaches to CA – conventional, directed and summative:

- In c*onventional content analysis* the researcher becomes immersed in the data to allow themes and insights to emerge rather than using preconceived categories. This approach is appropriate when describing a phenomenon or where there is little pre-existing theory or literature.
- *Directed content analysis* uses pre-existing theory or literature as its starting point, analysing the text to "validate or extend conceptually a theoretical framework or theory" (p.1281). It is considered appropriate where previous literature or theory would benefit from further exploration for the purpose of validation, countermanding or expansion.
- *Summative content analysis* analyses certain words or phrases in the wider text to explore their usage and underlying meanings. It is considered

appropriate for research questions examining the usage of certain words or phrases.

This research project used elements of all three approaches. While existing theory and literature were used to develop the initial research questions and concepts, coding quickly moved beyond these pre-defined categories to explore aspects that were raised by participants, which were further explored in subsequent focus groups and interviews explored. In this way data collection and analysis was sensitive to both current debates in academic literature and those factors considered important by participants. Keyword in Context employed a summative approach, as explained below.

Keyword in context (KWIC). KWIC recognises that words have multiple meanings and so examines specific words with regard to their co-locates (words appearing within a specified distance) to analyse these meanings (Fielding & Lee, 1998). KWIC was used to analyse words used with greater frequency, such as the use of the word "know" in the context of involving others, and to determine the layered meanings attached to this word. These meanings were then fed back into the CCA and CA, adding further layers of understanding.

2.4.2 Quantitative Data Analysis

The purpose of the study was to explore the *range* of participant preferences in response to the research questions raised in Section 1.6, not to provide a hierarchy of preference. Because of this, quantitative data analysis did not use mutually exclusive categories. Instead, within each theme and subtheme, the range of responses was identified along with the number of respondents who gave each response, keeping in mind that some respondents gave multiple responses.

Quantitative analysis was only conducted for measures where categories were mutually exclusive. Quantitative data were analysed using Microsoft Excel and the online calculators available at www.socstatistics.com (Stangroom, 2015). Due to the small sample size, Fisher's exact test was used to test significance of quantitative data as contingency tables were no greater than 2 x 2 and categories were mutually exclusive.

2.5 Research Validity

As mentioned, a mixed methods design was selected to allow qualitative and quantitative elements to offset each other. In particular, reasons for qualitative and quantitative aspects were as follows;

- The qualitative data collection strategies allowed an inductive methodology specifically attending to the priorities of the people being studied (Bryman, 2012; Burke Johnson & Onwuegbuzie, 2004).
- As it is inevitable that "the investigator and the investigated object are assumed to be interactively linked, with the values of the investigator . . . inevitably influencing the enquiry" (Guba & Lincoln, 1994, p. 110), semi-structured focus groups were chosen to allow the researcher to take a lesser role (Krueger, 1994).
- As qualitative research is often criticised for its subjectivity and lack of transparency and generalisability (Bryman, 2012; Leech & Onwuegbuzie, 2007), a quantitative element was incorporated in data analysis.

Specifically, it was hoped that the mixed-methods, multi-phase approach would systematically address the quantitative dimensions of reliability, validity, generalisability and replicability (Bryman, 2012) and their qualitative counterparts of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). This shown in Table 3 (overleaf).

Table 3.

Strategies to Increase Rigor and Quality of Research.

Domain	Strategies used
Credibility / validity	Analysis triangulation. Methods triangulation. Data analysis member-checked through sharing draft of results with participants.
Transferability / generalisability	Full transferability not focus of this research, as aim is exploratory. Use of thick description to "render a deeply detailed account . . . so that readers can judge the work's . . . application to other times, places, people and contexts" (Barusch *et al.*, 2011, p13). Quantitative data analysis may allow some generalisable inferences to be tentatively made.
Dependability / reliability	Analyst triangulation. Peer review. Audit trail of procedures used and decisions made in data collection and analysis.
Confirmability / replicability	Audit trail. Transparent and reflexive approach.

Credibility / (internal) validity. Validity asks "are these findings sufficiently authentic . . . that I may trust myself in acting on their implications? . . . Would I feel sufficiently secure about these findings to construct social policy or legislation based on them?" (Lincoln & Guba, 2003, p. 274). This speaks to both internal validity and external validity; credibility refers to the former while transferability relates to the latter and is addressed separately below. Credibility examines whether the research is a credible account of social reality as experienced by the people described (Bryman, 2012; Lincoln & Guba, 1985). Bryman (2012) argues for two strategies to ensure credibility; respondent validation (or member checking) and triangulation, both used here.

Member checking involves seeking feedback from participants to check understandings and interpretations (Bryman, 2012). Member checking occurred in data collection and data analysis. Throughout data collection, techniques such as paraphrasing and reflecting were used to ensure the researcher's understandings

matched those intended by participants. Participant feedback on data analysis was also sought by sharing a summary of draft findings with all but two participants (one whom was unwell and another who declined to review findings). Participants were encouraged to provide feedback; all endorsed the findings. However, this approach is not without criticism; participants may agree with the researcher's interpretation due to power differentials or a wish to please (Bryman, 2012). There is also a risk that participants may change their accounts or that the selection of one interpretation over another in cases of disagreement can reflect power imbalances (Barusch, Gringeri, & George, 2011).

Triangulation, using alternate sources of data collection or analysis to verify and augment findings, is recommended as it produces a more nuanced account (Barusch *et al.*, 2011; Bryman, 2012; Lincoln & Guba, 1985). Leech and Onwuegbuzie (2007) contend that at least two methods of data analysis should be used to increase the integrity of inferences drawn. This research used triangulation in both data collection and data analysis. At the data collection stage, two methods of data collection were used; focus groups and individual interviews, with the latter providing an opportunity to verify whether similar themes emerged outside norming group influences. At the data analysis stage quantitative and qualitative data analysis strategies were used.

Transferability / generalisability (external validity). Qualitative research, specifically focus group studies, are frequently criticised for their lack of generalisability (Bryman, 2012; Fern, 2001). This was not a significant concern for this exploratory research, which aimed to ascertain the range of views held by people with mental illness for use in future, generalisable, research. Yet the question still needs to be asked, how do we know the views held by these participants bear some relation to those held by people with mental illness as a whole?

To address this concern, Lincoln and Guba (1985) suggest the use of *thick description*; describing close observation of small instances rather than making sweeping grand statements, acknowledging that knowledge about a culture grows "out of the delicacy of its distinctions, not the sweep of its abstractions" (Geertz, 1973, p. 25). This description of observed phenomena in minute detail also allows others to assess

the transferability of findings to other settings or populations (Lincoln & Guba, 1985; Barusch *et al.*, 2011). This study allowed for thick description through the use of detailed transcripts, field notes and reporting of findings.

Dependability / reliability. Dependability asks whether others involved in the research would reach the same conclusions (Bryman, 2012; Lincoln & Guba, 1985). To establish dependability, Lincoln and Guba (1985) recommend developing a clear *audit trail*, recording all stages of the research and explicitly detailing why certain decisions were made. This research project has employed a similar approach and attempts have been made to 'lay bare' the rationale behind decisions to allow these to be challenged.

Peer review is also recommended to promote dependability (Bryman, 2012; Lincoln & Guba, 1985). At various stages of the project, ideas and concepts were shared with the research supervisor and colleagues in the field. This included a formal peer review of the research proposal by a leading colleague in the field. Transcripts and coding records were made available to the research supervisor, who scrutinised the data and conclusions drawn for theoretical and methodological integrity.

Confirmability / replicability. *Confirmability* asks whether the researcher has acted "in good faith" (Bryman, 2012, p. 392) and minimised the impact of personal values and objectives. In quantitative research this refers to research replicability; if the research can be replicated and the same findings obtained, this gives greater credence to the data (Bryman, 2012). In qualitative data, confirmability refers to the ability of others to confirm how conclusions were drawn. Two strategies were used to enhance confirmability; an *audit trail* (as described above), and *reflexivity*.

Reflexivity acknowledges that the researcher's values and attitudes will influence the choice of research question, research methodology, data collection and data analysis (Lincoln & Guba, 2003). Thus, a reflexive approach recognises that as a social worker employed in the mental health field and a student completing a Master's thesis, the researcher is from the clinical and academic fields already well represented in debates on incapacity. Without a personal experience of mental illness, the researcher is also an 'outsider,' although experience walking alongside people with mental illness meant she

had gleaned some 'insider' knowledge. In undertaking this research, these personal values and experiences influenced all research stages; for example an emphasis on social justice influenced the choice of research topic, design and methodology, as did the belief that constructions of incapacity are influenced by social, historical and political conditions. A reflexive approach encourages an acknowledgement of these assumptions, questioning these as much as clarifying them. To this end, reflexivity was not used in isolation but was instead combined with the above strategies to ensure the predominant 'voice' heard in the research was that of the participants.

2.6 Ethical Considerations

This project raised ethical dilemmas relating to informed consent, privacy and confidentiality, and guiding versus leading discussion. This section outlines an ethical framework and demonstrates how this was applied to resolve these dilemmas.

A discussion of ethical dilemmas must commence by first outlining the ethical principles used to resolve them. In developing this framework, Beauchamp and Childress' (2009) *Principles of Biomedical Ethics*, outlined four key principles:

- *Respect for autonomy*: Acknowledging the individual's right to "self rule . . . free from controlling interference and from certain limitations such as inadequate understanding" and to act "freely in accordance with a self-chosen plan" (Beauchamp & Childress, 2009, p. 99).
- *Nonmaleficence:* Recognising human beings as vulnerable and obligating the researcher to avoid harm.
- *Beneficence:* Asserting that intervention should contribute to the welfare of the individual or society. Beneficence is often contrasted with autonomy, with a contention that beneficence authorises others to act against someone's autonomous choice if it is to that person's benefit.

- *Justice:* Maintaining that all humans are equal in value, that all should be offered a 'fair opportunity,' and imposing a duty to prevent unfair exploitation and discrimination.

To these four principles, DuBois (2008) adds a fifth, *relationality*, the idea that human beings are "intrinsically related to others, a member of communities" and that "to flourish, actions must respect the relationships that an individual is in" (p. 34).

2.6.1 Capacity, Capability and Contribution

The most significant ethical dilemma faced was that presented by individuals who wished to participate in the research, but whose contributions could not be included. This dilemma was relevant for eight participants, for one of three reasons:

1. The participant wished to participate in the focus group but requested their contribution not be included in the research project (one participant).
2. The participant did not have a diagnosed mental illness (five participants; four were identified after focus group completion).
3. There were concerns about the participant's ability to give informed consent to research participation (two participants).

This discussion begins with arguably the most contentious of the above situations – capacity to consent to research – as the ethical reasoning in resolving this dilemma demonstrates a more exacting example of the same process followed in the other two situations.

This research was founded on the premise that capacity is socially constructed and that those affected by this construction are often excluded from debate. Yet at some point a decision needed to be made on an individual's ability to give informed consent for research participation. In particular, did some participants' inability to understand more abstract concepts mean they were unable to give informed consent, or was there a difference between *capacity* to consent and *capability* to meaningfully participate?

In deciding what action to take, the ethical principle of *autonomy* was key. Autonomy underpins the requirement for informed consent, however it does not necessitate that the individual has the *capability* to undertake a task (Beauchamp &

Childress, 2009; DuBois, 2008). Thus, a person may be *competent* to decide to go horse trekking but it does not automatically follow that the person is a *capable* rider. Similarly, a distinction was to be made between ability to give informed consent and ability to contribute meaningfully to discussion.

Informed consent involves disclosure of information by the researcher, understanding of this information by the participant, and his or her voluntary consent (Beauchamp & Childress, 2009; DuBois, 2008). Throughout the research project, care was taken to outline the study purpose and procedure, what would happen to information gathered, that participation was voluntary, and that individuals could withdraw at any time. To give informed consent, participants needed to understand these five things at a basic level and be free from undue influence. On this basis, most individuals who struggled with the more abstract concepts were still considered capable of giving informed consent to participate (just as participants in a drug trial are not expected to understand the exact mechanisms of the proposed drug on their body); only two failed at the level of capacity to consent. Tangential answers, misunderstandings and general issues relating to the 'quality' of participant contributions were deemed issues to be resolved through rephrasing, redirection and reflection.

However, there were two individuals whose capacity to give informed consent was uncertain. In both of these cases the decision was made to allow focus group participation but to omit their contributions from the research project. On what basis was this decision made?

First, it was deemed that they were capable of the autonomous choice to "be here in this group" – what was not certain was whether they understood that this was for research and what would happen to their information. In other words, they demonstrated capacity to participate in the group activity but not to participate in the research project. Thus the doctrine of autonomy encouraged respect for the individual's decision to participate in group discussion while questioning the appropriateness of using that person's information in ways he or she had not necessarily understood.

Second, the principle of justice stressed that "no persons should be denied social benefits on the basis of undeserved disadvantageous properties" (Beauchamp & Childress, 2009, p. 248). In other words, refusing to allow people to participate on the

basis of limited capacity may further exclude an already disadvantaged group. Should some participants have been excluded simply because their understanding failed to meet an arbitrary standard, although their 'lesser understanding' may have meant the project had particular pertinence to them? Morally, it felt that the answer should be no. Thus it could be argued that these individuals had a right to participate in the group, although there was a concurrent right not to be exploited.

The principles of beneficence and non-malevolence necessitate a balancing of risks and benefits to research participation. Risks to participation were deemed lesser than the benefits of participation; one host group facilitator specifically spoke of the marginalisation of her group attendees and her perception that they would benefit from participation and be harmed by exclusion from something they wanted to participate in.

Finally, as their comments were reflected on and incorporated by other participants, allowing these two individuals to participate in focus groups enabled them to contribute indirectly. This relates to the principle of relationality (DuBois, 2008); although their contributions may not be used directly, they nevertheless facilitated a richer experience for other group participants.

In sum, it was felt that by allowing these two people to participate in the focus group but advising them that their contributions may not be able to be used, a balance was struck between autonomy, justice, nonmaleficence, beneficence and relationality.

A similar decision to allow focus group participation but to exclude their data was made in the case of the five participants who did not have a diagnosis of a mental illness but who still wished to participate and the one individual who wished to contribute but who did not wish to be part of the research project. In each instance it was felt that:

- The individual was capable of exercising an autonomous choice to participate in the group in the knowledge that his or her contributions would not be used (*autonomy*),
- Although the participants' contributions could not be used directly, they may be valuable to the group as a whole (*relationality*),
- Given their history of exclusion, there was a case for allowing these individuals the opportunity to participate, however indirectly (*justice*), and

- The risks to participation were low (*non-malevolence*) while the benefits (in feeling they had contributed to something important) was higher (*beneficence*).

Whenever a person's non-eligibility was known in advance, this was discussed with the participant prior to commencement of the focus group, however this was not always possible.

2.6.2 Privacy and Confidentiality

Privacy and confidentiality touch on the principles of nonmaleficence and autonomy; respecting the individual's right to control access to, and distribution of, personal information while acknowledging that disclosure of personal information can cause harm (DuBois, 2008). Although confidentiality and privacy were stressed at all times and data were anonymised to protect individuals, three concerns remained.

First, while all data were anonymised, Dunedin is a small community and it is possible that participants could be identified by quotes used in publication. All endeavours were made to avoid using quotes that could render the individual identifiable, and participants were asked to approve quotes used. They were also reminded that they could withdraw from the research or request their quotes not be published should they have concerns about wider confidentiality.

Second, there is no guarantee that focus group participants will maintain each other's confidentiality (Carey & Asbury, 2012). Many groups already had their own codes of confidentiality and these were stressed at the beginning and conclusion of each focus group. Participants were reminded that they were free to leave the group or refrain from answering should they have concerns about confidentiality among group members. In fact, there was a sense that participants felt supported by fellow group members and this facilitated discussion.

Finally, related to nonmaleficence and confidentiality is the issue of required disclosure. As part of the informed consent procedure, participants were advised that where there were significant concerns about their risk to themselves or others, this may need to be disclosed to appropriate third parties. Fortunately, this issue did not arise within this research.

2.6.3 Leading, Guiding and Reactive Effects

A final challenge related to the boundary between facilitating and leading discussion, particularly when participants required more prompting. Traditional guidance stresses the importance of minimising verbal and nonverbal prompts to avoid leading discussion (Bryman, 2012; Krueger, 1994). However, both Rauktis *et al.* (1998) and Fern (2001) allow for a more directive style. Rauktis *et al.* (1998) comment that some people may be socially withdrawn or lack the cognitive or social skills for effective participation; accordingly, a more directive approach is needed to "nurture the talk" (G. Caruso, personal communication, 1995, cited by Rauktis *et al.*, 1998, p. 82). Further, while Fern (2001) contends a less directive style is appropriate for exploratory research, a more directive style may be useful where "the researcher is interested in uncovering shared experiences and knowledge about a particular phenomenon [and to] keep the group on track toward providing the necessary information" (p.85). A combined approach was used in this project to explore the breadth of participants' views while ascertaining their opinions on specific debates. This opened the project to greater researcher bias, however it is hoped that this was done in a way that avoided leading participants and encouraged disagreement with inferences drawn. Despite this, power imbalances and reactive effects (Bryman, 2012), such as the participant modifying answers to 'please,' are inescapable.

Chapter 3: Findings

As purpose of this study was to explore the breadth of participant preferences in response to the research questions asked in Section 1.6, the *range* of participant responses and the number of participants who conveyed each view are reported here. As most participants expressed multiple views, themes and sub-themes were generally not mutually exclusive and statistical analysis could not be conducted; those instances were categories were mutually exclusive are specifically identified in the text.

3.1 Participant Demographics

In total, 35 people took part in the research project; 27 in focus groups and ten in individual interviews (two people participated in both focus groups and interviews). Of the 27 focus group participants, data from seven participants were excluded due to failure to meet the research criteria of a diagnosis of mental illness (five) or uncertainty as to their capacity to consent (two).

The remaining 28 participants were aged between 20 and 67 years; 9 were male and 19 female. Participant diagnosis was grouped as follows:

- Psychotic disorders: Schizophrenia and schizoaffective disorders (10);
- Mood disorders: Anxiety, depression and borderline personality disorders (personality disorder was grouped in this category due to the symptom of emotional dysregulation) (13);
- Bipolar affective disorder (4);
- Other (Tourette's Disorder) (1).

Ten participants reported having multiple diagnoses, although only two reported diagnoses that crossed groupings; these were categorised according to the first diagnosis listed by the participant. Demographic details are summarised in Table 4.

Table 4.

Demographic Characteristics of Total Sample (N=28)

	Interview Participants [a] n = 10	Focus group participants [a] n = 20	Total [a] N = 28 (%)
Gender			
- Male	3	6	9 (32)
- Female	7	14	19 (68)
Age			
- Maximum	61	67	67
- Minimum	36	20	20
- Average	53.4	49.7	49.5
Diagnosis			
- Mood disorder	2	12	13 (47)
- Psychotic disorder	4	6	10 (36)
- Bipolar affective disorder	4	1	4 (14)
- Other	0	1	1 (4)
Ethnicity			
- NZ European / Pākehā	10	18	26 (93)
- Māori	0	2	2 (7)
Living situation			
- Live alone	5	8	11 (39)
- Live with spouse / partner	1	4	5 (18)
- Live with family	1	2	3 (11)
- Flatting / boarding	1	3	4 (14)
- Supported accommodation	2	3	5 (18)

Note. Percentages in parentheses. [a] Data from participants who contributed to both focus groups and individual interviews are replicated in both columns; duplication has been removed from "total" column.

Participants were asked to indicate whether they had been sectioned under the MH(CAT) Act, whether they had been assessed as lacking capacity, and whether they felt they had ever lacked capacity. These answers are shown in Table 5.

Table 5.

Participant Experiences of Interventions Overruling Decision-Making as a Function of own Beliefs Regarding Capacity (N=28)

	Participant beliefs re: capacity		
	Has lacked capacity n = 14	Hasn't lacked capacity n = 12	Doesn't know whether has lacked capacity n = 2
Has participant been under the MH(CAT) Act?			
- Yes	9 (32.1)	6 (21.4)	2 (7.1)
- No	4 (14.3)	6 (21.4)	0 (0.0)
- Don't know	1 (3.6)	0 (0.0)	0 (0.0)
Has participant been assessed as lacking capacity?			
- Yes	8 (28.6)	3 (10.7)	0 (0.0)
- No	2 (7.1)	7 (25.0)	1 (3.6)
- Don't know	4 (14.3)	2 (7.1)	1 (3.6)

Note. Percentages in parentheses.

In order to test significance of association between participant beliefs about capacity and those of professionals as demonstrated through detainment under the MH(CAT) Act or a formal assessment of incapacity, the "don't know" categories were treated as outliers and removed. The remaining two 2 x 2 contingency tables were analysed using Fisher's exact test; results are shown in Table 6 (overleaf).

Table 6.

Statistical Relationship between Participants' vs. Professionals' Beliefs about Capacity (N=28).

	Participant beliefs re: capacity		Fisher's exact test statistic (*p*) [a]
	Has lacked capacity	Hasn't lacked capacity	
Has participant been under the MH(CAT) Act?			
- Yes	9	6	
- No	4	6	.4283
Has participant been assessed as lacking capacity?			
- Yes	8	3	
- No	2	7	.0698 *

Note. [a] Significant p-values in bold (*p < .10, ** p < .05, *** p <.01)

While there is no significant relationship between participant beliefs about capacity and professionals' (possible) belief about capacity as indicated by detainment under the MH(CAT) Act, the correlation between participants who considered they had lacked capacity and those who reported having been formally assessed as doing so trends towards significance (*p* = .0698). This suggests that professional and participant perspectives generally agree on assessment of capacity.

For ease of reference, Table 7 (opposite) provides a summary of research participants, identifying their pseudonym, age, ethnicity, diagnosis and data collection method.

Table 7.

List of Research Participants.

Pseudonym	Age	Ethnicity	Diagnosis [a]	Data Collection Method
Anthea	44	NZ European	Anxiety	Focus group
Brooke	42	NZ European	Schizophrenia	Focus group
Camille	20	NZ European	Depression	Focus group
Cassandra	36	NZ European	Schizophrenia	Interview
Cate	61	NZ European	BAD [b]	Interview
Damon	44	NZ European	Depression	Interview
Daniel	43	NZ European	Depression	Focus group
Darren	28	NZ European	Depression	Focus group
David	67	NZ European	Tourette's Disorder	Focus group
Desiree	58	NZ European	Anxiety	Focus group
Dessa	56	NZ European	Depression	Focus group
Esme	42	NZ European	Schizoaffective disorder	Focus group
Faye	38	NZ European	Personality disorder	Focus group
Gabe	54	NZ European	BAD	Focus group and interview
Grace	58	NZ European	BAD	Interview
Jacqui	63	NZ European	Schizophrenia	Focus group
Julia	58	NZ European	Depression	Focus group and interview
Kim	34	NZ European	Anxiety	Focus group
Marjorie	60	NZ European	Schizophrenia	Interview
Paige	56	NZ European	Depression	Focus group
Pania	60	Māori	Depression	Focus group
Richard	50	NZ European	Schizophrenia	Interview
Rowan	58	NZ European	Schizophrenia	Focus group
Ruben	58	NZ European	Schizophrenia	Focus group
Sarah	68	Māori	Depression	Focus group
Simon	52	NZ European	Schizophrenia	Focus group
Tracey	55	NZ European	BAD	Interview
Warren	58	NZ European	Schizophrenia	Interview

Note. [a.] Primary diagnosis listed only. [b] BAD = Bipolar Affective Disorder.

3.2 Capacity Assessment

Examination of respondents' views on what factors should be included in capacity assessment highlighted a vast array of often contradictory views. Some participants felt that certain factors were irrelevant, others felt the same factors indicated a need for assessment, whereas still others felt the same factors should be determinative. The findings have been organised to reflect this; Section 3.2.1 looks at what factors should be considered potential *triggers* for assessment, while Section 3.2.2 looks at how a *determination* of capacity should be made.

3.2.1 Triggering Assessment

This section examines the range of participants' views on triggers for capacity assessment. Participants often held multiple, competing views, and the range of their responses is presented below.

Although this research presumed mental illness does not denote incapacity, for many participants the presence of mental illness was an implied trigger for assessment. Their views are described, as well as the degree to which participants felt emotionality, beliefs and values were relevant for capacity assessment and whether assessment should be based one's coherence with past selves, the ability of the present self to rationalise a decision, or the ability of the individual to consider future selves.

Unwellness, incapacity and authenticity. When asked to consider periods of diminished capacity 23 (82%) of participants opened by reflecting on episodes of mental unwellness, suggesting a perceived link between the two. Five participants, all with psychotic or bipolar affective disorders, identified a distinct break between their usual selves and their unwell, potentially incompetent, selves. Comments such as "normally I'm not like that" (Gabe) and "it wasn't the real Cassandra, doing that" (Cassandra) allude to a sense of disconnect, with the unwell self an inauthentic other

with whom they had to fight for control. This experience was not limited to people with psychotic disorders; Julia, who has had recurrent bouts of depression, similarly described a loss of control and feeling she was "fading away":

> You know, and that same part [which wanted to self-harm] stops you sleeping, that stops you eating and . . . I *couldn't have any control over that* . . . *You've lost yourself*. You know that you've lost, so you've got, so *you haven't got no sense of your own power* . . . *I say it wasn't me* . . . Because it was, it was like a sense of, *I was fading away*.

Yet while describing this 'unwell self' in terms implying inauthenticity, Julia also acknowledged it as part of her identity, and suggested that ultimately she had a choice over which self to 'align' with:

> It [the unwell self] *didn't feel separate* you see, it still, oh it's hard to describe, *it's not you . . . but it doesn't feel separate either*, it's not like anything that's come in at you from outside. I'll still take responsibility, I don't how else to put it, *it was still a part of me*. Yes, it was a part of me . . . Because it's only through, it was only through another aspect of myself that put its foot down and said 'NO', and *that's the part of me that I'm choosing to align with, but it doesn't mean that the other part isn't as much a part of me either.*

Among the above 23 participants, ten were unhappy that their capacity was doubted solely due to their mental state. However, three of these ten later reflected that unwellness could influence aspects of their capacity. This supports the contention that although mental illness may *affect* capacity and necessitate additional support, it does not denote total incapacity. Furthermore, all participants identified additional factors they felt should be considered and noted that each individual should be judged on a case-by-case basis. Cate, a woman with bipolar affective disorder, powerfully expressed this:

> [Speaking about the relevance of diagnosis] It's no different than having heart disease, so why should I be labelled or looked upon as very different, because I've got heart disease? . . . You know, that's what I think they should [do] rather than just judging us because we've got a label.

While acknowledging that mental illness does not wholly impair capacity, respondents also reflected on aspects of unwellness that may impinge on capacity. These are described in subsequent sections.

Emotionality, beliefs and values. The academic debates described previously identify the potential effects of emotionality, unusual beliefs and value differences in decision-making and capacity assessment. Respondents were invited to provide their views on the question, and their responses are outlined in this section.

Emotions versus persistent affective states. Nine participants described the impact of specific transient emotional states: of these nine, seven mentioned fear and anxiety, three suggested anger, and three raised distress. Respondents discussed the action of these emotional states on cognition, whether freezing thinking, increasing impulsivity or inhibiting decisiveness – "going round in your head" (Dessa).

Sixteen participants reflected on the influence of *persistent mood symptomology*. This included 12 participants who were diagnosed with a mood or bipolar affective disorder and four with a psychotic disorder. Participants identified several ways in which persistent mood symptomology influenced decision-making, many identifying more than one. Seven participants commented that persistent affective states influenced cognition, whether speeding, slowing or disorganising thought processes:

> *Not being able to think through a process* because you're just, you're just *shut off*, that's probably it. (Anthea)

> I have had worse depressions, where I can't, you know, where *I can't think, I just lose my ability to actually use my mind.* (Julia)

> Like there's a fulla who comes here often, *who just freezes*, you can't talk to him or nothing, he *just shuts everything out* . . . Like, like he's got a switch and *he's turned off.* (Rowan)

Four commented that their mood-state narrowed their focus, inhibiting the generation of options or limiting their perception of these options, something potentially incorporated in the MacCAT category of 'reasoning:'

> You can um, when you're in a situation, you just, *it's almost like you've got blinkers on and you've got tunnel vision, you see what you want to see*, and what you think is happening, whereas that

> might not necessarily be the case, 'cause you might not be looking at a wider scope of things, you're just not capable of seeing the bigger picture. (Damon)

Three individuals described how a major depressive episode affected their ability to attach any emotional significance to identified options; not 'caring' enough to decide. This is linked to the MacCAT domain of appreciation, the ability to consider the decision as personally relevant:

> *You just don't care* about anything, you've got no, you've got no um, compassion about anything, *nothing seems to matter anymore*, no matter how serious it be, nothing. *Just nothing matters*. (Cate)

These persistent emotional states were often seen as 'not who I usually am.' However, Grace, a 58-year-old woman with a diagnosis of bipolar affective disorder, disputed this, noting the subjectivity of judgements on whether emotional states are 'authentic' or 'inauthentic.' Instead, Grace identified her exuberant emotional state as integral to her identity and resented any implication that decisions stemming from this were inauthentic:

> I laugh too much and because it's in the books that if you're a bit high and laughing that's classed as a mania, but *it's just me being who I am*.

Unusual beliefs and failing to believe. Twelve participants felt that unusual beliefs impaired their decision-making. Participants diagnosed with disorders with a psychotic component (like schizophrenia or bipolar affective disorder) were more likely to express this view than those with mood disorders (eight participants with a psychotic disorder [57%] versus four with a mood disorder [31%]).

Where beliefs were seen to undermine decision-making, four types of 'interfering' beliefs were identified; those outside of one's control, 'fantastical' beliefs, a 'failure to believe' and denial. These belief systems overlapped considerably, with participants identifying more than one type.

For four of these twelve participants, such as Cassandra, a 36-year-old woman with schizophrenia, certain beliefs were considered external and outside her control:

> And all of a sudden I got this, these delusional thoughts, that, it's really crazy, you know it's really crazy shit . . . but I started

> getting these delusional thoughts . . . [that] somehow I had to become a Christian *against my will*, or become Jesus Christ *against my will*.

Six participants, such as Gabe, a woman with bipolar affective disorder, acknowledged periods when their belief systems lost touch with reality – "in fantasy land." However, this was not limited to people with psychotic disorders, as illustrated by Julia, who had experienced recurrent depressive episodes:

> The other bizarre thing that happened after that was that I still believed that I was gunna die. So even although, even although I had, had put, you know, put my foot down if you like, and said NO, I'm not gunna do it, I still believed that it was gunna happen somehow. So I, something in me truly believed that I was gunna die.

Seven participants experienced a failure to believe in options or appreciate the reality of their decision-making:

> So, you know if someone says well know that this would help you . . . sometimes it's like okay I hear what you're saying and I understand it, *but I don't believe it*. (Damon)

> Yes, it's like as though you're making a decision *but it isn't real*. It's, it's not imaginary but you don't know what it is either. It is sort of real but it's not. Now that's Chinese! (Cate)

Whereas the above participants seem to *want* to believe but can't, several participants also commented that denial or lack of awareness of their deteriorating mental state influenced their decision-making:

> I stopped taking the medication 'cause I actually thought I was a lot healthier than what I was. (Damon)

Value differences. Participants had some difficulty in engaging discussion on the influence of unusual values, perhaps because this was inadequately explained. The seven who engaged in this discussion acknowledged that people hold different values and a clash of values does not denote incapacity; what is important is *consistency*:

> Well I think, it wouldn't necessarily be if people thought if it [your values] was odd or unusual, but *if they thought it was odd or unusual for you*. (Kim)

For two of these seven participants, the relationship between unusual values and unwellness was key. For example, when discussing values in anorexia, Tracey, a 55-

year-old woman with bipolar affective disorder, suggested that anorexic values stem from unwellness, and that this unwellness determined incapacity, rather than the values themselves. Similarly Gabe felt that a significant change in her values from frugality to extravagance indicated unwellness, compromising her capacity:

> Interviewer [INT]:
> And so what's important to you is managing and saving your money?
> Gabe: Yeah
> INT: But at the time of being unwell, that went out the window?
> Gabe: Went out the window. Went out the window. That's a, that's a classic . . . *It's a classic symptom*, high spending money, yeah. '*Cause normally I'm not like that* I'm more frugal.
>
> (Focus group discussion)

Both Tracey and Gabe saw their unwell selves as inauthentic, suggesting that rather than unwellness, authenticity was the determining factor, as alluded to by Gabe in her final statement above.

Four of the above seven participants felt the determining factor in capacity assessment was not how unusual a person's values were, but whether the consequences of decisions arising from these values were 'risky' or 'dangerous:'

> And also, I guess if, if there was a way that *you could see that their decision would be potentially harmful* or, really drastic or something [then that should come into consideration]. (Kim)

This idea relates to the issue of risk relativity in capacity assessment, discussed further below.

Past, present and future selves and risky decisions. The 24 participants who commented on whether assessment should consider one's coherence with past selves, the ability of the present self to rationalise a decision, or the ability of the individual to consider future selves were fairly evenly split in their preference. This is shown in Table 8 (overleaf).

Table 8.

Participants' Preferences on Relevance of Past, Present or Future Selves in Capacity Assessment.

	Coherence with past selves	Present ability to rationalise	Ability to consider future selves
n	10	12	14

Note. Total views expressed (36) exceeds total number of participants who expressed views (24) as 10 participants expressed more than one view.

Ten participants indicated a preference for more than one approach. For example, Camille, a young woman with depression and post-traumatic stress disorder, wanted her present ability to explain her decision-making to be taken into consideration, balanced by an understanding of what she was "usually" like (past selves). The remainder of this section explores the rationale used by participants for prioritising past, present or future selves in capacity assessment.

Present selves: Decision-specificity and the MacCAT. The participant quotes highlighted so far suggest that the standard to gauge capacity should be the ability of the present self to explain their decision-making. This was a view expressed by 12 participants and succinctly articulated by Daniel, a 43-year-old who has experienced significant depressive episodes:

> Are they changing their mind cause of what they're going through and they're not thinking properly, or *are they changing their mind because they've thought of a better idea* than that the doctors have?

Daniel further suggests the individual be required to "rationally" and "logically" explain their decision-making. He felt that assessment ought to consider the ability of the 'current self' to provide a clear rationale:

> Is the person able to think *logically . . . or be rational . . . Is there is there some logic there* that the person can actually be able to think enough to be able to know what's going on with themselves . . . Like if they were to fall over, would they have known that? Or would they hold on to their leg and go 'my knee's sore?' (Daniel)

This requirement ties closely with the reasoning, understanding and communication domains of the MacCAT, and was a view shared by 11 other participants.

Changes from past selves. Eight participants agreed than sudden changes from past selves should lead to their capacity being questioned. For seven, the degree of change was relevant, particularly if it was ""extremist" (Jacqui) or out of character:

> Like a spontaneous, random idea, that's just changed . . . it would make you think that this person has had routine of thought for all these years, and all of a sudden, something's cropped up, and they're saying I want this, and *it's out of their characteristic* to say that. (Daniel)

Similarly, previous comments referring to unauthentic or uncharacteristic thoughts, feelings and experiences all referenced a 'changed' self.

For three participants, sudden changes from past selves were indicators of unwellness. For example, a previous quote by Gabe illustrated how she viewed changes from her past, frugal self to a profligate spender as an indication of diminished capacity.

Future selves / risk-relativity. Fourteen participants suggested that the ability to consider future selves was a prerequisite for capacity. All of these participants considered risky decisions to be indicative of diminished capacity:

> And I mean, it, it's kind of, I don't know, it could get really borderline but I mean, you know, if you were trying to decide between investing your millions in a reputable company or, getting it all out the bank and setting it on fire, you know I mean *there's some decisions where you've pretty obviously gone off the rails*, so from that perspective, I think *you could use that as an indicator* that maybe you're not capable of making good decisions at that point. (Kim)

Reasons for this stance fell into two categories. First, failure to consider the (potentially risky) implications for future selves was considered indicative of a lack of understanding or awareness, as suggested by Richard, a gentlemen with schizophrenia:

> Yeah, I would probably say that health professionals who know the, who can see the consequences better from their perspective, would, should override a, a person who kind of might have, sort of, not that same sort of *awareness*.

Similarly, Cate, a woman with bipolar affective disorder, felt that her ability to consider the future implications of her decisions demonstrated her capacity, despite this being questioned by others:

> [I] felt I understood the implications of what was going to be happening if I did or if I didn't [do this.] . . . [I was] thinking through like the consequence, like if . . . you did this, this would be the consequences.

Second, 'risky' decisions could indicate a deteriorating mental state, and potentially deteriorating capacity. Again, Richard best summed up this stance:

> [Speaking about the symptoms of his first period of unwellness, during which he believes he lost capacity] I'd done some really stupid things. That in hindsight could have landed, could have ended terribly. Uh, I know, for a start my, my diet pretty much, I wasn't eating properly. And uh, yeah, I lost a lot of weight. I was putting myself in situations like hitch-hiking that were a bit risky.

This suggests that the indicator of diminished capacity is unwellness rather than the 'riskiness' of decisions.

3.2.2 Determining Incapacity: An Individualised Approach

The above comments on assessment triggers all suggest a proviso: while any of these *could* indicate incapacity, none should *determine* incapacity. Two arguments were cited to back this contention. First, six participants took a human nature / civil liberties stance; that people had a right to their views and to change their minds. This was a position held strongly by Brooke, a 42-year-old woman with schizophrenia:

> It's your own choice, *everyone changes in their life* . . . I don't think they can use that, to, as a justify [a judgement of incapacity]. I mean . . . doctors change their mind all the time, why can't we?

Others took a contextual view, arguing that extenuating circumstances may justify an apparently unusual decision. For example, when discussing a hypothetical scenario where a person chooses to be homeless (a risky decision), Esme and Paige indicate the need to look beyond the decision:

> Esme: If it was a really clear cut decision like being homeless or living in a beautiful house [it should be examined]. But *sometimes it's not as clear cut as that*.
>
> Paige: Mmmmm. You may not be able to live in the beautiful house for some reason, *there's something going on behind the scenes*.
>
> (Focus group discussion)

Although participants expressed multiple views on the degree to which assessment triggers are relevant to capacity determination, there was a consensus in favour of a holistic capacity assessment that considers the individual, their context, and the degree of control they have over decisions. This section explores respondents' views on such an assessment.

Know the individual. The idea that capacity assessment requires knowledge of the individual came through strongly in discussion.

There was almost unanimous agreement that decisions about capacity be weighed in light of the individual's biography and circumstances; that an assessor must have an understanding of the individual as somebody with a unique personal and historical context – knowing 'who they are' and evaluating the impact of other factors in light of this understanding:

> So yeah I would say that, um, there should be, a lot of different factors involved in making the decision, so things like history and context and stuff and, you know, how difficult the decisions are that you're making, and how weird the choices are that you're choosing, and *how they all fit in with you* and your history and stuff. (Kim)

For example, when discussing the relevance of unusual beliefs, five participants maintained that decisions founded *prima facie* on 'patently untrue' beliefs could still retain a degree of internal rationality and be considered competent if understood in light of one's idiosyncrasies. Jacqui, a 63-year-old woman with schizophrenia, revealed how her superstitions beliefs about the number six would, in a hypothetical scenario, prevent her from building on their adjoining section (which is number six). For other group members this was an irrational decision based on an unusual belief, but for Jacqui this was a logical decision based on her personal reasoning. Thus, apparently unusual beliefs can form the basis of a competent decision as long as one's 'personal reasoning' is sound. Similarly, Kim, a 34-year-old with generalised anxiety disorder, points out that 'common-sense' requirements for capacity, such as logic, could be applied differently depending on the individual:

> But then I mean I guess that could be difficult '*cause some people are more illogical*, especially in decision-making, some people are really not very logical at all, even when they're well.

This theme – that capacity assessment needs an intimate knowledge of the individual – overlaps considerably with a second theme; that others involved in capacity assessment or decision-making need to know the individual. This is discussed in Section 3.3, which examines the qualities required of those involved in capacity assessment and decision-making.

Knowledge of the individual also often entailed an ability to recognise changes signalling incapacity; 15 referred to changes in behaviour or a deterioration in functioning as a potential indicator of diminished capacity. Conversely, nine participants, some of whom had cited lack of functioning as evidence of diminished capacity, considered retained functional ability as evidence *for* capacity:

> [How can others tell you can make your own decisions?]: I take my own medication, I dress my own self, I make my own bed, I do me own dishes, I do me own cooking . . . I can do pikelets, I can do scones. I cook roasts, I do chickens. (Desiree)

However, somewhat ironically, two participants with bipolar affective disorder cited functioning 'too well' as a potential indicator of diminished capacity:

> The whole house would be, every day would be absolutely spring cleaned from top to bottom, you just can't stop you've just got, you cannot sit you can't . . . you feel you just haven't got the power to sit, you can't sit still for two minutes. (Cate)

Know their context - including barriers to capacity and interpersonal dynamics. Twenty one participants felt assessors needed to understand the compromised individual's context. Two reasons were given. First, an understanding of context could explain behaviours that might otherwise call capacity into question:

> It might be a religious thing, you might suddenly had like an epiphany or something and, God's come to you or something and you might be suddenly spouting off all this religious stuff, and *people might think you're unwell, but really you might just be having a spiritual experience*. (Esme)

Second, understanding of context could reframe the question to prioritise capacity-restoring interventions, negating the need for assessment: 19 participants identified impediments to capacity (such as assessment environment, medication, physical health and interpersonal dynamics) they felt ought to be considered in assessment. This was clearly expressed by Julia, who felt that others should have sought to understand her situation and her fears when she last became unwell with depression, rather than reducing the question to competence or incompetence:

> And what's, yes and what's going on for you. What happened, what's happened, that you've come to this point. And it may have been, it may have been the history from six months back, it may have been three months back, *but what's been going on . . . that that you've become like this, it's so important*. (Julia)

Of this 19, seven participants stated the physical environment – especially the psychiatric hospital – exerted a detrimental impact on their mental state and their capacity:

> Well say, well say someone went up to [psychiatric] hospital and they were already feeling scared about something, they went up there, and there was patients worse off than them *that made them even more scared*. Well then someone will just think that they're naturally, that it's their own paranoia. (Daniel)

Medication was another oft-cited influence, identified by 15 of the above 19 participants as relevant. Of this 15, ten participants that medication had interfered with their capacity:

> There's no, there's no two ways about it, *I can talk about several drugs that just completely and absolutely blow you*. (David)

However, nine participants (five of whom also raised the capacity-undermining effects of medication) acknowledged that the right medication could facilitate capacity:

> My doctor still won't take me off my depression pills. And I agree on that too. I don't want to go backwards, I'm going forward now. (Sarah)

Five participants spoke about the impact of physical health on their capacity and mental wellbeing. This included the cumulative impact of extended periods of decreased functioning, such as the impact of poor sleep, inadequate nutrition and medical conditions:

> A lot of it's like you know you don't get enough sleep and you're eating properly, so therefore you're, you're not sort of thinking straight. (Damon)

> I had a urine tract infection . . . it hadn't been picked up. Um, so I went quite loopy. And I didn't know what I was doing. (Tracey)

Another potential influence on capacity, interpersonal dynamics, was identified by 12 participants. As Cate explained, professionals' attitudes towards the individual can shape one's capacity:

> Professionals have to try and be positive, and over last three months, they've been very negative towards me, and that's hard if you go there feeling positive and they've got negative at you, *you come away . . . in a big question mark*, like a mixed emotion, what do you do? (Cate)

In a related vein, seven of these 12 participants considered consultation with others a hallmark of competent decision-making. Cate, for example, described a competent decision she had "discussed . . . with family or whoever" versus an incompetent decision where she did not consider implications for others. The view that competent decision-making involves considering others was shared by five participants, as described by Warren, a 58-year-old man with schizophrenia who believed that competent decision-makers make decisions that are 'right' for themselves and others:

> Right, you've got life. You've got love, you've got family, children, family, grandchildren . . . How many does [your decision] affect? The whole family . . . And one, one wrong decision, one decision, could affect six or seven people . . . it could, could affect numerous people.

Control. Finally, a key factor in determining capacity identified by nine participants was the degree of 'control' they felt they had over their decision-making.

This lack of 'control' was evidenced in a number of arenas. First, 'control' was alluded to when discussing the relationship between capacity and mental illness, as referenced in the quote by Julia in Section 3.2.1 where she speaks about having "lost myself" and not having "any control."

Second, when discussing emotionality, participants alluded to the degree of control they felt they had over decisions stemming from persistent emotional states. For

six participants such as Faye, a woman with borderline personality disorder, this was about being able to handle one's experiences or to control one's actions:

> Because if you're too happy *you could get out of control* and do something dangerous.

Conversely, for three participants, a persistently depressed mood reduced their ability to pursue a course of action, a "block" that prevented one from acting on decisions. This was eloquently depicted by Damon, a 44-year-old man who had recently experienced a severe depressive episode:

> It was a bit like, okay knowing what to do, okay you've gotta take your first step, and it's like *not being able to find the start line* . . . It's a bit like having an emergency phone call to ring or something or another. Now you know, how to use the phone, and you've got the phone number, but you can't, I couldn't, I couldn't make that connection to pick up the phone and use it and talk to somebody, even though I knew that that's something that I had to do, *I just couldn't bring myself to do it*. For whatever reason . . . It's almost like *there was a block there that the brain couldn't make the connection to*. And be able to sort of act on it, there was just something, *there was a break there that, didn't make the connection*, although I knew the, I knew the connection, thinking about it, but putting it into action, there was just something there that *pprft* and it stopped.

Finally, control can also relate to control over one's beliefs. Cassandra, discussing her recovery, acknowledged that although she still had occasional unusual thoughts and beliefs, they are no longer outside her control, and, by implication, they no longer influenced her decision-making.

3.2.3 Summary

The above findings paint a complicated picture of capacity assessment. While respondents considered many factors potentially relevant, none was seen as conclusively so, and many participants identified multiple interacting dynamics. Capacity was not considered something that could be assessed by measuring its constituent parts, such as one's 'emotionality' or 'appreciation,' against an arbitrary standard. Instead, respondents felt that capacity depended on whether the individual felt their decision (or behaviour) was authentic, understandable in light of their

individuality and context, and within their control. What emerges is a request that assessment consider each individual holistically, on their own merits:

> They [capacity assessors] should have a more open mind. About everything, not be a closed, to me it seems still got this closed book thing, they go by the book of 1640 rather than look out the square . . . And not everything is a text book type thing, you know what I mean? . . . And I think that everybody should be taken on their own merits, judged individually, not, you know, collectively, so to speak. (Cate)

3.3 Involving Others

Although this project aimed to ascertain views on involving others in *decision-making* during incapacity, the desire for capacity assessment to be individually contextualised also compelled discussion on the involvement of others in *capacity assessment*; who should be involved, the qualities of this person, and issues with involving others. Participants held multiple, overlapping, and contradictory views. The following section explores their preferences.

3.3.1 Who Should be Involved

Participants nominated a range of people to be involved in assessment or decision-making, with equal emphasis on formal and informal supports. Informal supports included family/whānau (spouses/partners, parents, siblings, children or wider family) and friends, while formal supports could be further divided into health professionals (psychiatrists, general practitioners and community mental health clinicians) and support services (support workers or staff at drop-in centres). Participants often identified more than one preference; these are displayed in Table 9 (opposite).

Table 9.

Participant Preferences for Involving Others.

Preference [a]	n	%
Formal supports	22	78.6
- Medical [b]	*10*	*64.3*
- CMHT [c] staff	*7*	*42.9*
Informal supports	21	75.0
- Family	*19*	*67.9*
- Friends	*7*	*25.0*
NGO [d] supports	11	39.3
Other	10	35.7

Note. Items in italics indicate sub-ordinate groupings. [a] Categories not mutually exclusive; several participants identified more than one person. [b] General Practitioners and psychiatrists have been combined as 13 participants referred to these interchangeably or ambiguously. [c] CMHT = Community Mental Health Team. [d] NGO = non-governmental organisations

The figures show a clear overlap, explained by the fact that 12 participants explicitly endorsed the involvement of two or more people while several implied the same by naming more than one person in discussion. However, some participants had difficulty naming someone they wished to have involved, named someone they wished to have involved but who was not able to do so, or named people reluctantly. Similarly, as quickly as one person was named by a focus group participant, often another participant found reasons why a similar person would not be suitable in their case. This led to a discussion on the qualities required of involved others and potential barriers to nominating certain people.

3.3.2 Attributes of the Other

This section describes attributes considered essential by participants when nominating others to be involved in capacity assessment or decision-making. Three related and overlapping themes recurred time again when discussing the required qualities of involved others; knowledge, trustworthiness and a relationship.

Almost all participants (27) mentioned a desire for involved others to have knowledge of some description, yet the knowledge required varied. An analysis using

Keywords in Context (KWIC) identified 91 instances (by 20 participants) where the word know or its derivatives were used to describe the qualities of involved others. Two other terms, trust (54 instances, 16 participants) and understand (23 instances, 10 participants) were subsequently identified and analysed using KWIC. Four categories of usage were identified;

a. Describing the knowledge they wanted the other to hold, whether
    i. Personal,
    ii. Medical, or
    iii. Practical
b. The qualities facilitating trustworthiness,
c. The importance of a relationship with involved others, and
d. Describing the consequences of having the right person involved.

These categories were further explored through an analysis of the transcripts identifying instances where similar themes were raised. Again, participants often expressed multiple, overlapping views; these are described in detail below.

"Know me inside out."

Personal knowledge. For 24 participants, 'knowing' was about feeling that the nominated other knew them as individuals. More than just abstract knowledge, it was about a feeling that involved others understood them, knew them inside out, and could empathise with their situations:

> I think they'd have to sort of, like know me inside out. (Cate)
>
> 'Cause he knows what I feel like. (Faye)

For eight of this 24, an ability to understand the individual's reasoning was essential:

> And I explained to her why [I felt this way] . . . But, that was a realistic reason, and she knew the realistic reason, *but a lot of other people wouldn't understand* that realistic reason. (Dessa)

Ten of the above 24 emphasised a need for involved others to see their potential; not only did they want to trust this other, but they wanted the other to trust *them*. This may be due to interpersonal dynamics as discussed in Section 3.2.2:

> Well because they know my history, so, you know they know what I'm like . . . *So he knows what I'm like and what I'm capable of.* (Tracey)

> The staff have been really forgiving, and they saw, they saw, *they saw the potential in me* . . . they are very forgiving and they saw the potential in me to get out of that behaviour, and I'm very, I forever grateful to them for doing that . . . Believing that they believed in me, them believing in me, it just, it made all the difference. (Cassandra)

Nine of the above 24 participants identified the need for others to know their personal history, while seven raised the need for others to know and understand their current situation:

> . . . Who's grown up with you all their life, and knows, knows your individuality . . . Well they've got the understanding of you . . . Well they've got the understanding of you, they've known you . . . from when you're small. (Warren)

> Who knows your, who knows your history and everything: You. (Pania)

Conversely, this sense of wanting to be known was frequently described in the negative by participants who expressed frustration that others did <u>not</u> know them.

"Know my illness" – medical expertise versus a deeper understanding. While involved others needed to know the person as an individual, 20 participants also cited the need for knowledge of their illness. However, the nature of this knowledge varied. For 17 of this 20, knowledge of one's illness referred specifically to knowledge of one's medical history or to medical and mental health expertise, acknowledging that professionals have knowledge and skills that a lay person may not share:

> Well the same thing applies right throughout the, right throughout the human existence. If you want a doctor, you go to the doctor – you don't go to a lawyer. If you want a lawyer, you don't go to an accountant. So the same thing applies medically. (David)

However knowing one's illness also related to 'knowing what to look for' (nine participants), while seven participants referred to a deeper understanding of their *experience* of illness. These two usages have a broader application than just medical professionals and are highlighted by Cassandra when discussing involvement of her adoptive mother:

> Cause she knew my sym- [symptoms], knew a lot about the ill- [illness], she knew about me, talking about the illness and that. . . *She'd had an experience with me*.

Practical knowledge: Know what to do. Twenty participants felt that involved others should "know what to do." Again, this was sometimes linked with medical expertise and training (five participants). However seven participants associated 'knowing what to do' with 'good' decision-making, a vague concept whose usage included experience making decisions for another (as described by Richard) and someone who could be trusted to make based on 'what I would want' (as described by Cate):

> Ummm, well, I think, mum's pretty much able to make decisions for, for my dad, 'cause my dad's starting to deteriorate because of onset of dementia. (Richard)

> But they'd have to learn, I'd want to have their trust, that un-blotched trust that whatever they did, would be, in my interests if I couldn't do things by myself. (Cate)

Esme, a woman with schizo-affective disorder, commented that involving someone who does not know what to do can be disempowering for both the individual and their support people:

> No, I didn't [want to involve my family]. Because they, I found them, I just found that they, just didn't know what to do, they were pretty helpless.

This implies a need to empower nominated others, and was a view shared by Julia, who described others "project[ing their] powerlessness onto me."

Sixteen participants wanted involved others to have advocacy skills. Participants differed in the roles they specified for advocates and who was best placed to fill these. For example, when participants wanted advocates to promote an understanding of themselves and their history, they considered people personally connected with them to best fill this role:

> Well, if it happened in the hospital, they could refer back to the family doctor. And the doctor would give all the information to the other doctor. (Warren)

However, ten participants saw advocacy as providing an impartial perspective, checks and balances, or mediating between parties; in this case inclusion of people

skilled in mediation or balancing multiple perspectives, such as lawyers, judges, or independent advocates was mooted:

> So that's when you need a type of advocate to sit there and go . . . 'hold on, you're not listening to what she's saying.' . . . *Who's gunna listen to you, and listen to the other person* and know that the other person isn't listening, and to be able to say to the other medical people 'hey, you're not taking into consideration this and that.' (Daniel)

Trustworthiness – what is it? Whether the knowledge held by the involved other was personal or professional, participants needed to trust them. Trust in involved others was specifically raised by 16 participants, whether as a positive quality in those they would involve, or a deficit in those who they would prefer not to involve. Yet trust is an ambiguous, subjective concept. Using KWIC, the qualities most commonly associated with trust were:

- Someone who has knowledge – in the broadest sense as described previously (five instances, four participants),
- A good decision-maker (six instances, five participants),
- Someone who possesses a range of qualities associated with a respectful, validating relationship.

As the first two qualities have already been discussed, the remaining section examines those qualities associated with a respectful, validating relationship.

Trust was closely aligned with a perception by participants that they were heard, validated and taken seriously. This view was shared by 14 participants, most of whom related experiences where they felt ignored, belittled or undermined:

> [Would you trust your husband?] Oh I don't know, he um he might not realise that I'm as crook as what I was and not worry about it. (Paige)

This desire to involve someone who will consider their views is particularly relevant when considering the role participants want others to take in decision-making when capacity is diminished, discussed further in Section 3.4.1.

Eleven respondents emphasised the "human qualities" that are key to trust – a range of attributes they saw as facilitating the establishment of a relationship such as empathy, kindness, compassion and a non-judgemental approach:

> [When asked to list the desired qualities of involved others] Empathy . . . Understanding. Caring, kindness . . . umm. Patience . . . yeah, patience, caringness, kindness, um . . . Positive outlook on life, really. (Cassandra)

> He's a bit of a hard goer, and, um . . . you know, it's just a bit of a giggle with [my brother]. But he is, *he is just absolutely gorgeous* and . . . yeah, *he's a good man*. (Marjorie)

> Actually you need tenderness and to be cared about. (Julia)

Finally, three participants either alluded to, or specifically mentioned, the need for others to be honest and transparent. In six instances, this was in direct connection with the word trust:

> Yeah, I'd want them to be honest, and trustworthy, have an open mind, about things that are. (Cate).

> Depends if you trust them. Cause I thought I trusted my family. Trust is gone. Majorly gone . . . Well they went behind my back, and talked to the [community mental health] team. (Grace).

The importance of a relationship. Eighteen participants expressed the need for a relationship between them and involved others, a feeling that the other was emotionally invested in them:

> And that *he loves me very much*. Yeah. And he's proud of me . . . which is really good, that is just wonderful. (Marjorie)

> [I can ask them] are you really *interested in my wellbeing and my state of mind* and my medication? And if they say yes or no . . . that's the key. Then you know, you can trust them. (Grace)

> It's just that you know that they, *they're into you, they're on your team*. (Julia)

Ten participants acknowledged that this could take time; for some it was someone whom they had known "from when I was small" (Warren), for others it was about the time required to build "a pretty good rapport" (Darren). This requirement for

a relationship also points to the need for others to be reliable and available – "to be there when I need" (Marjorie), often despite having been put "through a hell of a lot" (Damon).

Thirteen participants acknowledged that developing a trusting relationship requires a degree of reciprocity; they need to share themselves and "open up" to the other:

> Again I think it depends on really who knows you best, who can you trust and *who you've opened up to more*. (Camille)

Key therefore is need for a relationship, built over time and involving a degree of self-disclosure. However, respondents also acknowledge that any relationship can fluctuate, influencing the degree of trust invested in the other:

> Well I've usually used my PDN [psychiatric district nurse], although . . . *[lately] it's been very, very intense, very, very difficult* because she's been so negative and I've been so positive. (Cate)

> I don't know if I could trust [my sister] with my [EFTPOS] card. But I sure trusted her when I had my [broken leg] . . . But if I had to go into [psychiatric] hospital I don't know if I could trust her, she might take money out then. (Gabe)

The benefits of involving the right person. The importance of knowing and being known was an unexpected finding. Julia, a woman with a history of depression who had recently experienced her first psychiatric hospitalisation, poignantly described how feeling "known" was a transformative experience felt deep inside:

> Because you <u>know</u> when someone touches the real you . . . Then you can touch the person really at where they're at . . . they don't have to hold your hand physically then, '*cause you can feel that, you can feel that they know . . . And then because they know you, something in you, goes ping. And it calms you down* . . . And then it sort of gets combed out, and combed out and calmed down and calmed down. And then eventually, like, it could transform right there in a few moments, you know, the woman [in me] starts to come. Because the child [in me]'s been soothed.

This feeling of being known and trusting another brought a sense of relief and calm, perhaps because it implied a sense of security and predictability – knowing what the other would do – facilitating help-seeking and co-operative behaviour:

> Like, like, say with me, at the time I wasn't really too worried about decision-making . . . so I was leaving things up to the psychiatrist and the nurse, and to make decisions, because its, I'm kind of like 'I'm in your hands now, I don't know what to do.' . . . It was real helpful, because . . . *that gave me some sort of security* in knowing that things aren't weren't going to get worse and worse and worse. (Daniel)

> I trust [my psychiatrists]. And if they were to make decisions then I'd go along with them. But I didn't know who the judge was, and who, whom was representing me and, *I didn't know those people so I didn't trust those people*. (Tracey)

3.3.3 Barriers to Involving Others

Many participants identified reasons why they would not involve certain people. Four potential barriers were identified; problems identifying specific individuals, complications within the relationship, participants' personal difficulties involving others, and others' unavailability.

Difficulties related to specific individuals. Suggestions by focus group participants to involve specific individuals were regularly 'voted down' by others due to a perception that the named person lacked the necessary qualities. At least 13 participants voiced this concern, although vocalisations and non-verbal body language suggested that most had someone they did not want involved for the similar reasons. For example, Brooke, a woman with schizophrenia who had experienced others deciding for her despite her belief that she retained capacity, argued that no one knew her well enough:

> Well the psychiatrist, you know, they've studied med and they've studied psychology and psychiatry. But *that doesn't mean to say they know you inside out* . . . You go to a hairdresser once a month, and they can do your hair but they can't run your whole life. Well, same with the psychiatrist – they can't, they haven't seen you for your whole life, and suddenly you're in [psychiatric hospital] for five minutes and they think they know all about you and they can make decisions! And I know a lot more about me than they ever will, and they may never see me again, so why should they have all that power?

Similarly, at least four participants expressed a concern that others may not fully understand their circumstances:

> [Speaking of a staff member at her support centre] He reckons, reckons we should just be here for a short time . . . and *he doesn't understand anything like that 'cause he's never had any illness or anything like that himself*. (Dessa)

Eight participants expressed concern that others may have ulterior motives or personal agendas. This included professional or institutional agendas:

> It was just 'well you've been in hospital too long, *we want you out of here*, we're gunna give you ECT [electroconvulsive therapy].' (Tracey)

> Esme: But the judge seems to agree with the doctors most of the time anyway.
> Paige: See the judge isn't a doctor is he?
> Esme: And he thinks to himself, '*oh well the doctors know best*.'
> (Focus group discussion)

Nor were family and friends considered immune, although participants acknowledged that this may be due to family members' desire to be seen positively or a tendency to deny cause for concern:

> But some parents, some family people, don't wanna believe. They think that they've brought you up badly so you've got a mental illness. *But the family don't wanna think it's their problem* . . . [so] the family want you to go to hospital *so they get away with blame for badly raising you badly* and making you mental. (Brooke)

> Well [my husband] might do, he jus- he just doesn't think there's anything wrong with me. Yeah. Yeah. Or *he doesn't want there to be anything wr- anything wrong maybe* . . . So it's sorta, shove it under the mat. (Anthea)

Eight participants identified that others may not be best placed to assist with capacity assessment or decision-making due to youth or their own issues. Others acknowledged the immense challenge associated with capacity assessment and decision-making, with four participants specifically identifying the potential for burnout:

> Um, my youngest daughter, she loves me to bits . . . She didn't want to come home when I was cutting. She did catch me at one stage . . . and she was horrified, and then she was worried that she would come home and one day I'd just, I wouldn't be alive

> sort of thing, so she actually, she didn't want to come home . . . So that affected her. (Damon)

> And I think that's why my marriage split up now that I think about it, 'cause my husband couldn't cope with it, *he didn't know how to cope with it* . . . 'Cause it was, I'm not easy to live with when it's like that. No one is. (Cate)

Issues arising from interpersonal relationships. The desire for a relationship with involved others was a key finding. Yet relationships are dynamic and participants identified unhelpful – even toxic – elements undermining their ability to call on certain individuals.

Three participants simply described a lack of a relationship or personality conflict as a barrier to involving others:

> My parents are both dead and I don't get on with my family, or they don't get on with me. (Paige)

Four participants cited abuse, whether physical, financial or psychological;

> I don't trust my mum, cause sometimes she's nasty to me . . . Mum knewed [my sister] was beating me up and stuff like that, hitting me and stuff like that. And my mum used to do that to me a long time ago too . . . My mother took to me and stuff like that, 'cause when she gets nasty and stuff like that she does that, that's why I don't trust my mum sometimes. (Desiree).

However, six participants mentioned more insidious power imbalances, a feeling of being pressured into certain decision:

> I don't know, 'cause I've, every time I have a decision, especially with my family, *they seem to talk over me* . . . And they, they tell me, this decision, and I just agree with it, and um, so it just keeps the peace, so yeah. (Pania)

On the other hand, seven participants expressed concern that being 'too close' could affect a person's ability to be impartial or provide the required support:

> Yeah, so it's a bit like, this is what I want; let's just say *my mum wants to sort of be more on my side sort of thing*, so she's more inclined to sort of go with me, even though it wouldn't really be in my best interests. (Damon)

Personal barriers to involving others. Fourteen participants acknowledged personal reasons for their reluctance to involve others, whether due to an inability to trust others, concern about being a burden, or fear of dependence.

Just as 'trust' can vary depending on the decision, the context and the person involved, six participants reflected that their ability to trust others had been compromised by their experiences. This was true for Grace, a woman with bipolar affective disorder, who felt her fragile ability to trust (something she felt she was never taught) had been betrayed:

> It's sad, I thought I trusted people, I trusted people too much. Now I'm backing off.

Conversely, recognition of the gravity of capacity assessment and decision-making, combined with a fear of being a burden, prevented five participants from asking others to be involved:

> Yeah but friends aren't, no, I wouldn't, *I wouldn't want to put that on to anybody* ever, that situation. (Dessa)

Finally, five participants acknowledged that certain mental states allowed them to be more easily led by, or dependent upon, others. Although not necessarily a barrier to involving others, this has implications for the role others should take if the goal is to facilitate capacity:

> Yeah well, I know that when I'm unwell, *I can get very susceptible to what people say*, so if some people tell me to go do it, I won't take two thoughts to it, I'll just go and do it. Which normally I don't, I actually think about things. (Camille)

Availability. Availability was cited by 12 participants as a barrier to involving others, whether geographical distance or availability in a crisis situation:

> That's a bit hard on you though, if, if they [the nominated support person] *were uncontactable for a period of time*, and you were sort of stuck in hospital or [the emergency psychiatric service] or wherever until they came. (Esme)

Even when people were readily accessible, infrequent contact, feeling rushed, or frequent changes in (professional) support people limited the opportunity to form trusting relationships. Anthea, a woman with a diagnosis of anxiety and depression, felt

strongly about this. She was discharged from the mental health team as soon as she became well, only to be re-referred when her mental state deteriorated. Due to discontinuity of service, she felt she was not supported when she needed it most:

> I've been through mental health and I've become well, so they've discharged me . . . I was signed off, and meanwhile that I was signed off I had no one to talk to – this is the thing, I want someone to talk to when I need to. In the meanwhile I had no one to talk to, everything's getting built up and built up and built up . . . the doctor I saw recently said 'oh yes, we'll send a nurse out to you once a week cause you really need help at the moment you've got a lotta things going on,' and I says 'well of course I have when you sign me off and put me back in the files all the time.'

Unexpectedly, two participants felt contact with preferred others was limited by their care team. Both felt disconnected and isolated from people they felt should have some involvement:

> Yeah I would like my mum involved, but . . . the . . . organisation that I'm under, mum thinks that, my organisation doesn't want, that I'm saying that I don't want my mum involved, but I do. (Faye)

> Because sometimes they won't let you have . . . psychiatric lawyers, free lawyers, to go to the judge. And sometimes they won't let you see the judge for a year, and the judge is going to let you out of [psychiatric hospital], and they only let you see the judge every two years – well that's two years lumped in [psychiatric hospital] waiting for a judge and a lawyer. (Brooke)

Stigma and social isolation. Combined, these barriers culminated in an experience of stigma and social isolation. This was felt several ways. Six participants felt their contributions were ignored due to the stigma associated with their diagnosis:

> Well some, some people will, some people too don't believe you because you've your illness. Depending on your illness they can say they don't believe you. (Dessa)

Warren and Richard, two men diagnosed with schizophrenia, spoke poignantly about potential support people 'stepping back' once they became unwell:

> Well, a lot of people, you might make, might meet friends, say about thirty friends. Then you have, get a mental illness, only ten of those might come round and see you. The others step back, and they don't want to have anything to do with you. (Warren)

> I mean, yes, if you broke your leg, then, then sort of, I think then there's people coming to help. But if it's mental illness, I dunno I think, people might just, stand off. (Richard)

The direct consequence of this stigma was social isolation, with few people participants could call on, let alone people who had the desired qualities:

> It would be good to have a few people, but there's not all that many people who can actually, um, do that [be involved], you know. (Paige)

> It's a bit different when you're on your own because you've got nobody. (Cate)

The interconnectedness of these barriers can become a self-fulfilling prophecy; experiences of stigma make it more difficult for participants to trust others, in turn limiting the network they can call upon. This is demonstrated in Figure 1 (overleaf).

Figure 1. *Interconnectedness of Reasons for Reluctance to Involve Others*

3.3.4 Deciding Who to Involve: A Personal Choice

Participants felt they should control who was involved in capacity assessment and decision-making on their behalf. Twelve spoke about their desire to involve more than one person, feeling this would overcome individual shortcomings and ensure holistic assessment and decision-making:

> I don't know, I feel like for me personally the more people that are involved in making the decisions the more likely it is that they'd make good decisions. Or that they'll make decisions that I would want made. 'Cause if you had just one person, then maybe, like, I don't know, maybe there'll be certain areas where they have like a pet issue, or they think you should do things differently or you know, and um I guess, the other thing is my sister's a nurse and she's doing psych nursing at the moment so that would be quite helpful. (Kim)

Involving more than one person also promoted mutual support. Pania, a Māori woman closely connected with her whānau, described the support provided by her extended family:

> Yeah my family, they're pretty good, they're pretty cool people . . . Some of them have got more or less problems as well, so we're all, we're all together, and we all sort of help. It's like a big whānau, and you know, so *we sort of each help one another*, and, yeah. (Pania)

However, David, a 67-year-old man with Tourette's Disorder, disagreed, stating that "too many cooks spoil the broth," while a second person, on receiving feedback on the research findings, specifically disagreed with involving more than one person.

There was significant debate on whose opinion should hold sway in case of disagreement. The majority of the 17 respondents who commented on this topic felt final authority should rest whomever they nominated to hold this role, followed by whoever knew them best. Others felt it should be a majority decision or that there should be a hierarchy of decision-makers. These views are summarised in Table 10 (overleaf).

Table 10.

Preferences for Prioritising when Involving More Than One Other.

Participant view [a]	Number of participants (n = 17)	Percentage of total respondents on this topic
Participants' nominee	8	47.1
Person who has best knowledge of participant	7	41.2
Person who has greatest expertise	5	29.4
Participants' own view	5	29.4
Majority decision	2	11.8
Hierarchy of decision-makers	1	5.9

Note. [a] Categories not mutually exclusive; five participants shared two views each, three participants expressed three views each.

3.3.5 Summary

Respondents varied widely in whom they wanted involved in capacity assessment and decision-making during periods of diminished capacity, and the appropriate balance of personal, medical and practical knowledge. Yet most agreed that they wanted to be able to trust and have a relationship with involved others. Developing this relationship takes time, yet the benefits are vast, resulting in a sense of security and facilitating help-seeking behaviour. Despite these benefits, participants were often reluctant to involve certain people. Stigma and isolation played an underlying role, and some participants were unsure whom to call on in times of need. Participants wanted authority over whom to involve and who should have final say if decisions are disputed. Ultimately, rather than generating a specific list of who should or should not be involved, respondents emphasised the desire to decide for themselves:

> You have to be very careful about who that person was, making those decisions, because you see . . . some people are listeners and some people aren't . . . And some people who on the surface may appear big and strong are actually being driven by their own fears and perceptions about things . . . just because they've got the loudest voice and seem . . . the most capable, [they] are not necessarily the person to be listened to. So they make out they are, 'cause they come across so well, but actually, in this

> experience for me it's more likely to be someone far quieter. And who actually listens. And has a, a feeling about what's going on. You know. For me, that's far more suitable. (Julia)

3.4 Decision-Making During Incapacity

The previous section explored participants' views on selection of *who* should be involved, whether in capacity assessment or decision-making. This section examines *how* participants want these people to be involved and what principles they feel should guide decision-making if capacity is diminished.

Attempts to quantify respondents' preferences for decision-making during incapacity were unsuccessful; preferences were vague and many participants expressed more than one view; an initial partiality to a certain approach, followed by a secondary preference if the first was unworkable, with a final overriding imperative. Experience of making decisions alone and with the involvement of others seemed to play a part in the development of preferences; for example, Faye, who lived in supported accommodation where others presumably exerted a greater degree of involvement, more readily devolved decision-making than Julie, who had lived a 'normal' life raising her son and did not have contact with mental health services until her 60s. Three examples illustrate the complexity of participant views:

- Gabe, a woman with bipolar affective disorder, initially expressed a desire to remain involved in and be supported with decision-making should her capacity be diminished (wishes principle, current self, supported decision-making). She later acknowledged that perhaps some decisions should be withheld when she was unwell. Subsequently, she decided to set up an advance directive (wishes principle, past self) to specify what decision-making authority she wished to retain (wishes principle, current self) versus that which she wished to devolve to nominated others – who she hoped

would balance her future wellbeing with her past and current wishes (a form of surrogate decision-making balancing a wishes and a best interests component).

- Kim, a woman with a history of anxiety, also wanted to be supported in her decision-making should her capacity be diminished (wishes principle, current self, supported decision-making). However, she wished to nominate a 'committee' who could make decisions on her behalf should her decision-making put her at risk (advance directive nominating a surrogate). While this implies a best interests, future-oriented stance, her requirement that this committee consist of people who know her implies that best interests consider her how her *past selves* define best interests.
- Like her co-participants, Brooke felt that she should be involved in all decision-making. However, her experience of bullying and discrimination and her distrust of mental health services meant she did not wish to share decision-making at all and saw any veto of her decisions as a violation of her rights (strong wishes principle, current self). Should she not be able to make decisions unassisted, she wanted only nominated others who were well-schooled in her wishes to act as advocates and ensure her (past) wishes were respected (strong wishes principle, past self).

To make sense of this diversity in preference, the following section explores participants' usual preferences for *others' role in decision-making* and how this might change if capacity is diminished, before outlining participants' preferences for *principles to guide decision-making*. It concludes by exploring difficulties associated with supported decision-making identified by participants.

3.4.1 Preferences for Own and Others' Involvement in Decision-Making

Participants differed extensively in their preferences for involvement in decision-making. To make sense of responses, a preliminary examination of transcripts using constant comparison analysis (CCA) identified participants' preferences for involvement and support, irrespective of their capacity. Keywords in context (KWIC) was then used to further explore participant preferences when capacity was diminished, using ten

terms and their derivatives identified through CCA. In total, 120 quotes were identified from 25 participants. The terms and their usage are shown in Table 11:

Table 11.

KWIC Terms and their Usage when Describing Own or Others' Involvement in Decision-Making when Capacity Intact or Diminished.

	Usage	
Term	n = 120	%
Ask [a]	6	4.8
Communicate [b]	3	2.4
Discuss [c]	8	6.5
Input [d]	5	4.0
Involve [e]	8	6.5
Listen [f]	10	8.1
Respect [g]	3	2.4
Say [h]	46	37.1
Talk [i]	17	13.7
Tell / told [j]	14	11.3

Note. [a] Ask, asked. [b] Communicate, communication. [c] Discuss, discussed, discussion, discussions. [d] Input. [e] Involve, involved. [f] Listen, listened, listeners, listening, listens. [g] Respect, respected. [h] Say, said, saying, says. [i] Talk, talked, talking. [j] Tell, telling, told.

This KWIC analysis was fed back into the CCA, seven themes identified, and numbers of participants who expressed each theme were counted and categorised according to whether they referred to times when capacity was intact or diminished. The results are summarised in Table 12.

Table 12.

Themes Discussed when Describing Own or Other's Involvement in Decision-Making: Capacity Intact vs. Diminished.

	Capacity intact		Capacity diminished	
	n	% [a]	n	% [a]
Emotional support	12	42.9	10	35.7
Informal support	14	50.0	6	21.4
Advice / problem-solving	9	32.1	10	35.7
Compromised individual's views elicited / shared	3	10.7	14	50.0
Views Considered / negotiated	9	32.1	21	75.0
Support person's views shared / individual challenged	2	7.1	9	32.1
Devolve some decision-making	8	28.6	15	53.6

Note. Categories not mutually exclusive. [a] Percentage of total participants (N=28)

These results indicate the theme of 'informal support' decreased when discussing involvement when capacity is diminished compared with when capacity is intact. When capacity was diminished, more participants expressed a preference for their views to be elicited / shared, for these views to be considered, and for support people to share their own views and / or challenge the compromised individual. This could possibly be because this was a time when their views were more likely to be ignored.

Preferences when capacity is intact. Of the 22 participants who commented on usual preferences for decision-making when capacity was intact, all expressed a desire for involvement. However, the preferred degree of involvement varied, from six participants who felt they should, or do, retain one hundred percent of decision-making authority, to five who chose to devolve certain aspects to others, citing their own lack of expertise (eight participants).

> I like to, with anything now . . . I like to be my own, my own boss, so to speak, and make decisions, whether they be in your eyes or whoever's eyes right or wrong, I think that, that is irrelevant. I have to be given, I feel as though that I should be given the choice. That's the thing. (Cate)

While all wanted to be involved in decision-making, most did not want to do this alone. Fourteen participants spoke about the importance of informal support people; someone to talk things through and share difficulties with:

> I find that . . . even if you can't talk to your family, there is places like the club here, that you can . . . It's like one big family, and there's a lot of people that you can talk to, you know, one on one. You know even if it's just having a cuppa. (Pania)

This informal support – talking things through – overlapped but differed slightly from the emotional support offered by others; 12 participants (of whom ten had commented on the importance of informal support) spoke of having someone who backed them, understood them, and was truly *there* with them. Rather than just being able to talk things through, these people were important in providing the emotional backing so respondents could make their own decisions.

Nine participants wanted someone to give advice or help with problem-solving; to give ideas, another perspective, or feedback:

> Well um, get on to the right track, you know get on to the right track and uh, then uh, get things sorted out. (Ruben).
>
> They advise you, you know. (Sarah)

Preferences when capacity is diminished. In analysing the KWIC terms and themes relating to involvement in decision-making during periods of diminished capacity, five participant preferences could be placed on a continuum:

1. Retain complete decision-making authority,
2. Retain most decision-making authority, but to delegate specific tasks,
3. Forms of negotiated, shared or supported decision-making,
4. Complete delegation of decision-making authority, and
5. Being informed of decisions made by others.

Again, participants often expressed multiple, overlapping views, and these categories are not mutually exclusive. This section explores where participants believed the balance should be struck between their own involvement and that of others.

"I'm the one affected . . . let me do me for me." All of the 25 participants who commented on decision-making preferences during incapacity wished to retain input into decision-making. This view was held by Cate, a woman with bipolar affective disorder whose decision-making capacity had recently been questioned:

> Well, I think I should have the final say *because after all I'm the one that's affected* . . . I feel that I'm usually when I'm like that I know the signs [of becoming unwell] enough to be able to say, 'well look this is what has to be done or I need to go to hospital or I need this.' . . . With consultation with the psychiatrist. (Cate)

"Maybe I should have that decision taken away from me really." Although all aspired to retain decision-making authority, later discussion tempered this with a desire for input from others. This is clear in the above quote by Cate, who qualified her desire to retain decision-making autonomy by seeking consultation with the psychiatrist. Further discussion identified a tension between wanting to retain decision-making autonomy and acknowledging that occasionally some decision-making should be devolved. For example, Cate had arranged for her finances to be managed by a third party organisation yet wished to retain control over medication.

In Cate's situation we see a desire to retain *authority over what to devolve*. This was a view shared by Gabe, another woman with bipolar affective disorder, and Cassandra, a young woman with schizophrenia. All three acknowledged there were times when their capacity was diminished, yet all believed they ought to retain input in some areas. They sought authority over the demarcation of decisions to be devolved, expressing a sense that 'I know what I need.'

Supported decision-making. Almost all participants advocated forms of shared or supported decision-making when capacity was diminished; however they differed on how this should occur. The CCA and KWIC analysis identified three forms of supported decision-making:

- Listening, consideration and negotiation
- The illusion of choice
- Practical and emotional decision-making support;

"I like them to maybe listen and have a conversation": Listening, consideration and negotiation. Participants wanted their views to be elicited and considered, and for decisions to be negotiated. Fourteen wanted others to ask their opinion; over half of these described experiences where this hadn't occurred:

> Especially the last admission, they should've actually communicated with my family, or at least *talked to me properly, instead of just talking at me* . . . They did [listen] to begin with, and then they kind of went all no, this doesn't make sense . . . we're getting a doctor in, um, now we're getting you put under the act, here's a piece of paper saying you're under the act, and that's it, yeah. (Camille)

21 participants wanted their views to be considered and decisions negotiated. For example, in discussing the hypothetical scenario of the woman with dementia, Daniel spoke about wanting involved others to consider his point of view and incorporate it to the greatest extent possible:

> Um, I feel like, if there's a person that's going to kind of run through things, that lets you know what's going on, and then they're going to be explaining things, so that they bring you in with the decision, then you can go, 'oh yeah.' You can agree, or you can go 'well, that bit there, I don't mind but, you know, you can keep me in hospital but at some time I wanna go outside and

> have a smoke, so if you expect me to be in there for ten hours, I'm just gunna get real crappy.' You know, you know, or something like that. *So, having it that way, you get to have an opinion and say something, you know, but also being involved in the decision*. (Daniel).

However again an alarming number (14) described experiences where they felt their views were not considered:

> Well they should actually say, to, if I'm able to make the decision, Faye, would you really wanna do this, how we gunna achieve this, but instead they're saying, no Faye can't live on her own she's gotta have an organisation for the rest of her life. (Faye)

Nine participants wanted involved others to provide feedback; for example on their mental state. Of these, seven acknowledged that this may require challenges to their decision-making; an experience both helpful and intrusive:

> They actually did . . . make the conversation, make sure that, I was, you know, why I had done made the decision, *they actually talked me through that so that was good. But they did make it, make me feel small.* (Anthea)

Even when acknowledging some choice may need to be removed, participants wanted to retain a role in implementation. For example, Tracey felt that although she needed to be placed somewhere safe whilst unwell, she should have choice regarding the location:

> Well, I was in that scenario. I couldn't be left at home . . . And um, I needed to be, under supervised care. Which, that was fine, but, the facilities were really horrible. [Psychiatric] hospital's the pits. It's cold.

"I had a choice, but I didn't" – (the illusion of) choice. Although participants wanted their views to be elicited, listened to, and incorporated in decision-making, many included the proviso that their wishes be overridden if their choices placed themselves or others at risk; of the 21 participants who wished to be involved in decision-making, 14 gave some form of risk proviso:

> [Discussing the hypothetical scenario of a woman with dementia] Um, I think if she was to stay at home, and she really wanted to, you would have like a, *she would have to have a checklist,* she would have to understand that there would be a checklist for her, and if she didn't basically abide by the checklist, then it's like um,

> she's not capable of looking after herself at home . . . [And] you say 'well *these are the rules,* we understand that you want to stay at home, and that sort of thing, but we have to put rules in place, because you're forgetful or you've got Alzheimer's or something or another.' So we are looking out for, for her, and this is the only way we can keep her at home, as long as she does these things. (Damon)

Thus, participants seemed to be condoning a degree of protection; steps taken to facilitate their decision-making but with the condition that final consequences dictate whether or not these wishes are respected. For some, such as Darren, a young man who had experienced a depressive episode during which he was acutely suicidal, there was a clear illusion of choice:

> She [my therapist] decided that it would be, I should go into hospital. And um you know, she asked me if I would go in voluntarily, and initially I leaned very much no . . . And she kind of mentioned, you know, '*if you don't go to hospital I'm going to put you under the Act,*' so I was like, I had a choice but I didn't, sort of thing. And she gave me an easier out so it wouldn't, it wouldn't go as hard on me if I chose to cooperate, and I think that was, that was all right for me. *I mean at the time I was very angry at her . . . [but] I think that it worked out all right in the end*.

However, while nine participants, like Darren, condoned this illusion of choice, even he did not feel comfortable with it at the time, and similarly three felt powerless and undermined:

> Well because I've had another experience when they've said go in to hospital or we'll put you under the act as well, like, I actually find they quite often will say that. (Camille)

"They could help you make the decision." Thirteen participants wanted support with decision-making should their capacity be diminished. Support took multiple, overlapping forms; for ten participants it was about assistance with problem-solving such as prioritising, advice-giving or help identifying options. For example, Cate spoke about how a friend helped her to prioritise and focus when she felt overwhelmed:

> [He] kept saying to me these positive things, 'you're going to do it Cate. Cate, what have you got today and we'll just do, we'll just do two things today and then that's enough off your list, and be positive, be calm.' And it was him that got me through it.

Similarly, Damon stated that being presented with options facilitated his decision-making, including his resolve not to suicide:

> Um, for myself, um *there was options put forward*, and I could sort of see a way out . . . 'You might find this beneficial sort of thing would you give it a go?' And then it was 'yes I would.' *So okay I can make a decision* 'yeah I don't really wanna kill myself sort of thing' at that stage (Damon)

Support could involve helping someone to help themselves; equipping them with the skills to facilitate their decision-making and their recovery:

> Medication helped a, and b I helped myself, I had psychology, and psychologists that helped. And I helped myself too, it's been a combination. I've been having the right medication, b I've been helping myself, c the psychology. (Cassandra)

While problem-solving support is useful, 11 participants still identified emotional and informal support as important, as powerfully described by Julia:

> I remember [my friend] came out to help me [move house] . . . and when she came out, I just, tears just streamed down my face 'cause it was just like, 'thank you so much, *for being here and to come and help me*.' And then we just, *talked gently to each other* and we just carried on doing what we were doing.

"I'm in your hands now" – Devolving decision-making responsibility. Seven participants - four of whom had suffered severe depressive episodes, one with bipolar affective disorder, and two with schizophrenia – wished to abdicate *all* decision-making responsibility to another during times of diminished capacity. Their rationale depended on their diagnosis; for those who had experienced a depressive episode – like Daniel – this delegation of responsibility seemed a relief, a relinquishment to someone else in a time when they felt overwhelmed. However, for those with an experience of schizophrenia or bipolar affective disorder, the rationale for conferring decision-making wholly to another reflected the belief that they lacked capacity.

"But at least they still could have talked to me and told me why" – Being informed. Irrespective of individuals' preferences for involvement, five participants expressed a desire to be kept informed of decisions made, with two describing lack of information as a disempowering and frightening experience:

> I said 'well, *no one told me . . . they never discussed it with me*.' Made me really angry, in a rage more than angry . . . At least they still could have talked to me and told me why. Rather than just do it and then find out later. Cause I think the worst thing was, being told, not being told, just being given ECT and you didn't even know 1. What it was and 2. What will be the long term effects . . . After two years they tell you, but I mean they don't tell you. And not being told or shown what actually happens. (Cate)

Summary. While participants appreciated decision-making support to some extent regardless of their level of capacity, the preferred form of this involvement varied. When capacity was intact, participants appreciated informal, practical and emotional support – someone to talk things through and share understandings. When capacity was diminished, the emphasis shifted to listening, negotiation and collaboration; a joint endeavour to facilitate the individual's wishes to the greatest extent possible while allowing (for some) the scope for these to be overridden.

3.4.2 Principles to Guide Decision-Making

Participants were asked to consider whether they preferred decision-making during periods of diminished capacity be guided by their best interests or their wishes, and whether decisions should favour past, present, or future selves. In theory, these concepts can only be combined in four ways; a best interests decision usually prioritises best outcomes for one's future self, although could endeavour to restore a person's past self. Similarly, an individual wishes decision can only privilege past or current wishes – any decision couched in language of "this is what John would want in the future" must take as its reference either his past wishes or a judgement of his future interests. This is illustrated in Figure 2 (opposite).

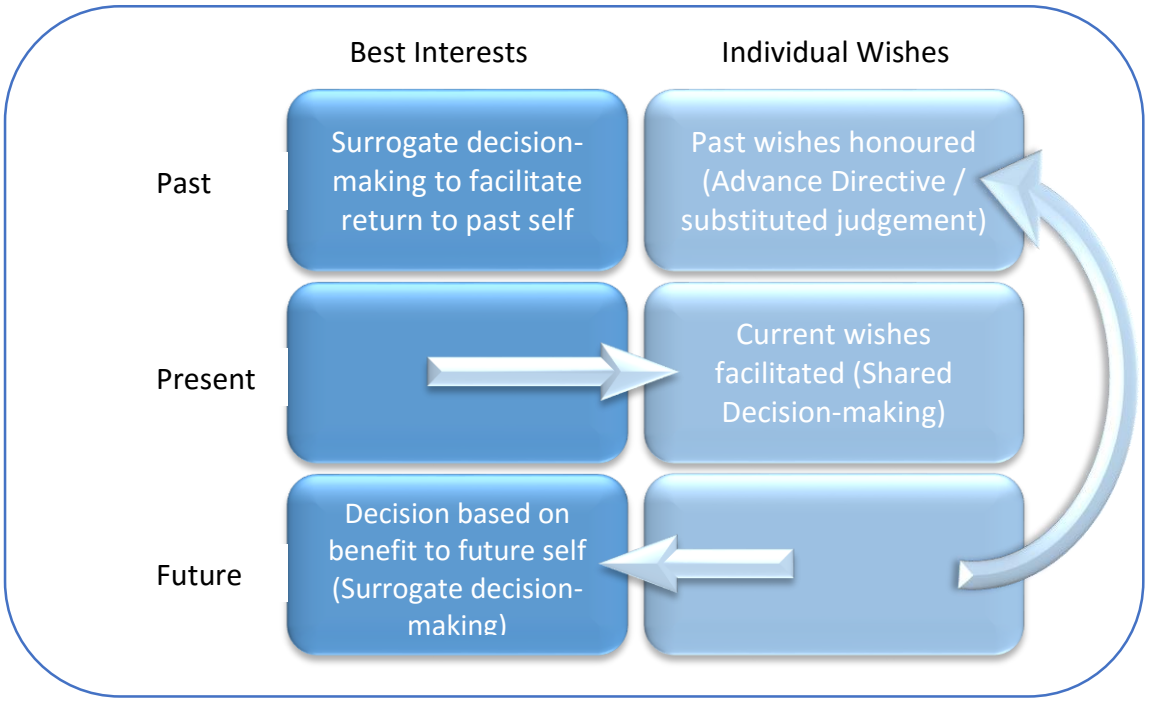

Figure 2: Possible Preferences to Guide Decision-Making during Incapacity

Participants' preferences for these approaches varied widely, often changing in response to new scenarios or considerations; this section explores participants' complex views of this topic.

Individual wishes: "I'd be very interested in being part of my own decision-making." Twenty-six participants expressed a preference for decision-making to incorporate their wishes to some extent, from complete autonomy, to supported decision-making or models incorporating advance directives or substituted judgement. This section explores the rationale for their preferences before exploring whether past or present wishes should be prioritised.

Rationale for wishes being followed. Three rationales were used to justify a wishes approach: A rights-based argument; decision-making involvement as facilitating recovery; and as a defence against subjectivity.

The rights-based argument, supported by five participants, starts from a respect for autonomy and self-determination, and a contention that removing one's decision-making authority undermines his or her rights:

David: Well it comes down to an independence I think . . . It gives you more, it gives you that authority – not so much authority – it gives you the opportunity
Brooke: Autonomy
Daniel: The power

(Focus group discussion)

The second argument, that involvement in decision-making is important for recovery, was raised by six participants, such as David:

> But if you're consciously aware, quite honestly, of what was going on, I'd be very interested in in being part of my own decision-making, *because that also helps to bring you back into society*.

Linked with these two arguments is the idea, raised by five participants, that decision-making is a precursor, indicator, and responsibility of adulthood. Conversely, lack of autonomy over decision-making is considered 'child-like:'

> And I said 'well after all I'm 61 years of age, *I'm not being told, I'm not a five-year-old.'* And sure you've gotta make some mistakes . . . I think it's time now that I just sit back and do, *let everybody just leave me alone let me do for me*. (Cate)

> Yes because you see what six-year-old child is going to take on, is going to manage responsibilities? If anything took me over it was that [child-like state] . . . *Because you believe you can't manage what's going on, you take yourself to a time when you didn't have to manage things* . . . And you need looked after . . . and you need someone to hold your hand, you <u>need</u> someone to do things for you. You become so needy, because you-, you don't, you've lost your own power, you don't feel that you're capable of doing anything to help yourself. (Julia)

Finally, four participants pointed out that because decisions are subjective, it is important their voices are heard:

> You know, someone might say it's good for you to hang glide out of a plane, whatever, bungee jump out of a plane 'cause it gives you a rush. But other people like a doctor or, chiropractor might say 'don't do it it's not good for you 'cause you'll hurt your back'. It depends - *what you think is good for you may not be what another person thinks is good for you*. (Brooke)

Past versus current wishes. Most participants preferred to be involved in decision-making via models of supported decision-making, indicating a preference for current wishes to be heeded in the first instance. However, two qualifications were

made. First, as discussed, 14 participants identified a risk proviso, implying a 'best interests, future selves' standard. Second, ten participants placed capacity-dependent constraints on involvement in decision-making, acknowledging the paradox of asking someone assessed as lacking capacity to be involved in making decisions:

> And if you could ask them, *if they weren't sort of too out to it*, that could be a good thing too. Although *they might not be in the right frame of mind* to be making a critical decision. (Esme)

Through discussing instances where current wishes may need to be overridden alternatives were identified. Participants expressed a preference for past wishes to inform decision-making via advance directives or substituted judgement models, discussed by 20 participants each. Twelve of those supporting advance directives intended to use these to nominate whom they wanted involved in decision-making, suggesting advance directives can facilitate substituted judgement.

Support for advance directives and substituted judgement was driven by participants' desire to guarantee their voices were heard, particularly if their compromised self was not capable of expressing a view:

> But the trouble is you might, think you want medication and then when it comes down to it, you don't. But I suppose you'd be overridden by what you've written in the past . . . I think I'd want it [my compromised wish] to be overridden really because you might not, you know, *you might, be not in a fit state to make that change* of your plan. (Esme)

However, despite her endorsement of advance directives, Brooke, who was acutely aware of mental health discrimination, was adamant that an advance directive should not be an automatic requirement for all consumers of mental health services:

> *It should be your own choice*. You don't go around saying someone has to, has to have, have a gun licence and if they don't have a gun. They don't carry a gun licence but no guns! You don't have to carry it, have it, have it in your purse.

Conversely, six participants considered that because the future is unknowable and circumstances change, attempts should always be made to follow current wishes as a first preference.

> I don't know, I'm always very hesitant to, have, things set in concrete, I guess, 'cause *you just don't know, what's gunna*

> *happen*, and I would hate to make an advance directive and be all like yes this is the thing I really want and then have it be something that was in the end a really terrible idea. (Kim)

Consequently, although there was support for advance directives, there was also recognition that they need to be reviewed and should not replace attempts to facilitate involvement in decision-making.

"It comes down to the best interests of the patient." As discussed, although most participants endorsed wishes-based decision-making in the first instance, not all shared this preference and others qualified their endorsement with a risk proviso. For these participants, the bottom line remained their 'best interests,' albeit often implicitly. This section examines participants' rationale and preferences on how this be applied.

Best interests and future selves: "It's for my own good." Four overlapping rationales were used to justify a future-oriented best interests approach; safety, one's own good, incapacity, and others care.

Eleven participants expressly identified risk and safety as paramount considerations when making decisions for another. For example when considering whether decisions should be overridden, Cate suggested this occur if she posed "a risk to myself," while Kim extended these grounds to include "also for others."

Although risk was the main justification for a future-oriented best interests approach, other rationales were also used. Key among these was the idea that others know best and that should decisions be made "for your own good" (Daniel) – the ends justified the means.

> The treatment was very horrible. It's quite barbaric. Admittedly I've come out the other side now, and I've got all my faculties with me. (Tracey)

Just as participants justified substituted judgement or advance directives as necessary due to their own incapacity, so eight of them cited their own incapacity or a belief that they would be so incapacitated that they "wouldn't care" (Pania) as a reason why others might know better. Damon made reference to this several times throughout our interview.

> And just, you're not in the state of mind, and regardless of, I might not accept it or something or another but that is the case. . . Regardless of what you think you are not right . . . so somebody else has to step in and basically say 'well, that's not the way to go.'
>
> I would like to think that what I would want would be taken into consideration. But then again, with talking with other people, they'll know better, because they're not in the mental state that I would be in.

Finally, there was a view, held by eight participants, that best interests decisions are made from a place of caring and that people are making these decisions to look after them; "they'd be wanting to *help her* by taking her card off her" (Dessa).

This approach is predicated on the idea that patients will eventually appreciate decisions made for them, best summarised by Cassandra, transitioning out of psychiatric hospital after an inpatient stay of more than eight years:

> I wouldn't be the way I am today without that [the appropriation of decision-making authority] happening. I mean I had to go through the process of learning . . . I actually think that's the main reason I ended up in hospital, was to learn that. It's the main reason I ended up in there.

Best interests and past selves. Although the above rationale for best interests defines it in terms of future selves, five participants tied their best interests to past selves, believing that they would be best served by respecting the wishes of, or facilitating a return to, past selves:

> [What principle should guide decision-making?]
> Jacqui: What's good for me.
> INT: What's good for you?
> Jacqui: Yeah. My husband's a saviour like that. He wouldn't let me go to a home without extreme need. There needs to be.
> Anthea: I think that's good; what is good for you.
> Dessa: . . . 'Cause if I got chucked into [a rest home] then that wouldn't be good for me, I'd hate it.
>
> (Focus group discussion)

For this focus group a decision that did not respect their past wishes on going into care could not be in their best interests. Likewise, for Warren, best interests decisions in one's own good must facilitate a return to past (well) selves:

> I had no big decisions to make or anything. If I had, I would have left it to the family . . . *For the best to get well*. They're do-, in other words, they're doing the right thing. (Warren).

Reversibility. For one focus group, best interests decisions were those with fewest irreversible consequences. Depending on who makes the decision, reversibility could relate to either future or past selves: If the decision is made by the patient and is considered risky and irreversible, the concept of reversibility asserts "don't let *me* do something that may cause me <u>future</u> harm." However, if the decision is made by another, reversibility requests "don't *you* do something that I cannot change back" – tying it to past selves. This idea of reversibility was discussed extensively by one focus group:

> INT: How do you guys define best interests? Because that becomes a very contentious thing, for some people.
>
> Darren: I think just something that results in a consequence that isn't extremely harmful, that isn't irreparable . . . Minimising, permanent kind of consequences.
>
> . . .
>
> Kim: Say something like um, electro convulsive therapy or whatever it is. Like that's potentially something that can be helpful but it's also potentially something that can be really terrible. So, I guess, from that view it wouldn't necessarily be in someone's best interests to have it, unless it was, unless all the other options were worse than that, 'cause otherwise you just end up getting screwed over.
>
> . . .
>
> Darren: Yeah . . . It doesn't need to be like the absolute best interests it's just an interest that is gunna get us through it with the least bad.
>
> Kim: Yeah . . . I mean I guess the theory is eventually you will once again be capable of making your own decisions, so the decisions that people make for you or on your behalf should be the ones with the fewest permanent consequences
>
> INT: . . . What happens if there wasn't a certainty that you would get your decision-making back? . . .
>
> Kim: Well again I would probably try the things that were the less likely to have bad outcomes first, 'cause if they work, then you're not risking a bad outcome.
>
> . . .

Darren: I think, stick with the emotional wellbeing, until something bad happens. Like you know that could be, the degree of bad could be potentially horrible, but I think that if that risk of the horrible thing isn't incredibly immediate, like maybe, if you think that you're gunna get some kind of a warning . . . you could use that as the point where you say, 'right now you need the care,' and sort of go through that with the person beforehand. So I think stick with emotional [wellbeing] until horrible things happen or something bad happens.

Kim: I think it depends how bad the potential bad things are, 'cause like if there's a possibility that you know, she's gunna set her house on fire or was [going to] die or something – I mean once you're dead your emotional wellbeing's really not going to be an issue either. So I mean if the potential physical consequences were something that you could either see coming and avoid or something that you could recover from, then maybe mental or emotional wellbeing is more important, but if there, if there's a possibility of serious physical consequences, that's probably not going to do a hell of a lot for your emotional wellbeing either. So, at that point, I guess, it would be better to move to a situation where you were less happy emotionally but at least you were still physically functional.

(Focus group discussion)

Summary. Participants' preferences for decision-making during periods of diminished capacity varied widely, often changing in response to new scenarios or considerations. In the first instance, most participants preferred decision-making a current, wishes-oriented approach maximising their involvement irrespective of capacity. However, when confronted with issues such as risk, ability and reversibility, participants' initial partiality for supported decision-making often gave way to secondary preferences, such as an advance directive, or an overriding imperative for a future-oriented, best interests model. Participant preferences were not readily reducible to a simple hierarchy of preferred models, indicating a need for individualised decision-making approaches during diminished capacity.

3.4.3 Issues with Supported Decision-Making

Participants demonstrated a complex understanding of the issues around decision-making during periods of diminished capacity. Barriers to involving others such as trusting the right person, availability and access, and issues around abuse and power have been discussed. Similarly, the potentially transient nature of one's wishes, difficulties in foreseeing one's future wishes and the paradox of deeming a person incompetent yet still seeking their involvement were acknowledged and contrasted with subjectivity in asking another to ascertain one's best interests. However participants also alluded to more subtle issues with supported decision-making, such as assertiveness, insight, dependence and interpersonal dynamics.

Involvement in decision-making requires a degree of assertiveness, particularly if systems or the individuals within systems do not seek to include them. Yet nine participants described difficulties speaking out, especially when they were already feeling vulnerable:

> Yeah well I'm not, I'm not one of those people that like to push myself to be out there, I like to be sitting in the background, and you know, if I have to answer, I'll answer. (Pania)

Fifteen participants feel their views were disregarded or overridden by others, an acutely disempowering experience:

> I just felt, completely out of control of the whole situation, and I had no control. And I just felt, I was in a pit, I was just suicidal, you know, I was just really, god, couldn't get my head around what they were doing, their treatment of me. (Tracey)

> And sometimes people don't listen to you and it makes you feel irrelevant. (Rowan)

Ten participants identified that although they wanted others to be involved in decision-making should they lack capacity, a concurrent lack of insight meant that they might not acknowledge this. This was particularly so for those with bipolar or psychotic disorders over those with affective disorders (six participants versus four), although it was often only with hindsight that they acknowledged their decision-making was compromised:

> It wasn't the right, it didn't feel right [having others make decisions], but I know it was now. (Cassandra)

> But looking back, I knew it had to be done. And I, I did fight it, I got a lawyer and everything, got my cousin to fight it, and we had the hearings at [the tribunal], but I was unwell. (Gabe)

Finally, although mandating the involvement of others in decision-making to some extent, two participants identified the potential to become reliant on their support people. For example, Marjorie acknowledged that her low self-confidence underlies a tendency to rely on others:

> They do support me sometimes, and I don't want to get too used to it, 'cause I'm meant to be making these decisions for myself, and I yeah I can do it. Other times I just feel a bit vulnerable and I just don't feel okay with it . . . Like I just say 'oh well you do it,' you know. And there's no need to . . . I can do it if I have to instead. I rely on support quite a bit . . . And that's, yeah it's not good.

3.4.4 Summary

Clearly there is no 'one size fits all' approach to decision-making during periods of diminished capacity; participants varied in the degree of involvement they wanted for themselves and others, the extent to which they wanted decisions to honour their interests versus their wishes; and whether they wanted past, present or future selves prioritised. Instead, an exhortation to 'let me choose how and whether to choose' seems to underpin participant views. Several informally commented how helpful it was to formulate their views in more abstract ways. This suggests that people appreciate advance treatment planning discussions which allow the opportunity to determine guiding principles to govern decision-making during periods of incapacity, rather than focussing on specific decisions.

Respondents also shared a desire to be viewed and treated as individuals – for decision-making to respect their values and preferences, even if that means overriding what they have specified. As stated most clearly by Kim:

> I don't know, we're still people. Just 'cause we can't make a decision right now doesn't mean that you, like, that you shouldn't still consider our humanity.

Chapter 4: Discussion

Read as a whole, this study's findings paint a complex picture of participant preferences for capacity assessment, involving others, and decision-making during periods of diminished capacity. While broad conclusions can be drawn, none is without nuance and qualifications. This section outlines the study's broad findings, introducing an overarching theme: relational autonomy. Limitations of the current study are identified, and implications for policy, practice and future research are discussed.

4.1 Research Findings

Participants held a range of views in response to the research questions, differing not only amongst themselves as to the factors considered relevant to capacity assessment, who they wished to have involved, and their preferences for decision-making should capacity be diminished, but also changing their mind over the course of discussion.

The fluidity of participants' views, often shifting in response to questions or group discussion, was a key finding, and has significant implications for policy and practice. While some participants had fixed ideas, for many life experiences, social interactions and new information will continue to influence their preferences; the views they expressed as part of this research project are unlikely to be the same views they would endorse one month or one year later. This is true of anyone, regardless of whether or not they have a mental illness, and simply reflects the dynamic and fluid nature of human preference.

Despite this, some overarching themes could be identified. This section will explore the research findings, beginning by exploring participant preferences in response to each research topic and concluding with a comment on an overarching theme: relational autonomy.

4.1.1 Capacity Assessment: Triggers versus Determinants

Participants, like academics, held diverse views as to what considerations should govern capacity assessment, with no single factor, including those enshrined in the MacCAT (Appelbaum & Grisso, 1995; Appelbaum & Roth, 1982; Grisso & Appelbaum, 1998, 2007; Grisso *et al.*, 1997, 1995), deemed conclusive. Instead, participants distinguished between the degree to which elements, such as emotionality, should *trigger* assessment or *determine* its result, with the degree of influence assessed according to three questions:

1. Is this understandable for *me*?
2. Is this understandable in light of my *context*?
3. Am I in *control* of my decision-making?

The first relates to authenticity; the notion of a stable self that is disrupted during incapacity (van Willigenburg & Delaere, 2005, in Sjöstrand & Helgesson, 2008, p. 116; Brudney, 2009; Sjöstrand, 2013). This disrupted self seems to underpin the connection between mental illness and capacity – the unwell self is not the true self, and therefore any decisions originating from this unwell self are not a true reflection of one's goals, aspirations or priorities. Thus, what is important is not one's emotions, beliefs or values, the degree of risk inherent in a specific choice, or whether someone suddenly changes their minds, but whether the decision *makes sense* to the individual with mental illness. This requirement for competent decisions to demonstrate internal rationality supports the proposal by some authors that capacity assessment incorporate a value assessment to scrutinise the consistency between one's value system and the decision being made (Banner, 2012; Berghmans, 2001; Buchanan & Brock, 1989; Charland, 1998; Donnelly, 2009; Sjöstrand, 2013; Sjöstrand & Helgesson, 2008).

The second question for capacity assessment asks 'is this decision understandable in light of my circumstances?' Participants felt strongly that context is

important; that a decision *prima facie* driven by factors undermining capacity can be understandable in light of one's context, whereas the same decision in another context could indicate incapacity. One focus group's discussion on burial versus cremation illustrates this point: for one participant a change in preference (coinciding with a time she was acutely unwell) reflected a reconsideration of her views brought about by her experiences; for another, a similar change was unthinkable in light of his personal commitments. Participants felt capacity assessors needed to understand the decision from their point of view and circumstances.

Participants also emphasised that incapacity can be created and perpetuated by factors such as medication, surroundings, or interpersonal dynamics. This finding is similar to that reported by people with mental illness in the study by Amnesty International (2009), and provides evidence for the social construction of incapacity. This stance, aligned with a Social Model of Disability, asks the assessor to consider factors influencing one's capacity and to address these, rather than focussing solely on capacity assessment. As put succinctly by Julia:

> 'Cause it's almost like saying well you either have to be perfect or you're imperfect, and there's nothing in between. And it's not taking into consideration, what's going on in your life at that time . . . Because if you're full of fear . . . then clearly it would be, to me, clearly that's the place to start.

The final question participants felt should be considered in capacity assessment asks, 'am I in control?' Lack of control relates to first order versus second order desires (Appelbaum, 1998; Hope *et al.*, 2011; Sjöstrand, 2013); a person may act on one set of desires although the 'real self' wants something different. Although participants acknowledged that both first order and second order desires form part of their identity, Julia alluded to *control* over second order desires when she chose which 'self' to align with, while her comment that "you haven't got no sense of your own power . . . I was fading away" similarly speaks to one's sense of command over one's self. Equally, control over first order versus second order selves underpins uncharacteristic behaviour such as Gabe's prolific spending and Damon's inability to act on a chosen course of action. Lack of control also explains the role of persistent emotional states in capacity; one can regain command over transient emotions, but a persistent inability to control one's emotional state may indicate subsequent decisions are inauthentic.

'Control' also supplements Parfit's 'psychological continuity' (1983 & 1984, cited in Craigie, 2013, p. 9), suggesting assessors should consider whether the individual feels in command of their actions. Comparing Gabe, whose change in self was brought about by a discrete episode of mania, with Damon, where the change was more gradual, psychological continuity would consider Gabe incompetent due to inconsistency with her past self, but Damon competent. Yet Gabe and Damon's lack of 'control' indicates both lack capacity, an assessment both would agree with.

In sum, capacity (or incapacity) is not only socially constructed, but personally constructed, and participants believe capacity assessment cannot be applied in a formulaic way *a la* MacCAT. Rather than objective judgements as to whether one is 'too emotional' or 'not logical enough,' participants feel the weight given to these assessments must be mediated through the individual's authenticity, context and control, with capacity determinations based on the individual's, not the assessor's, filters. This is demonstrated in Figure 3.

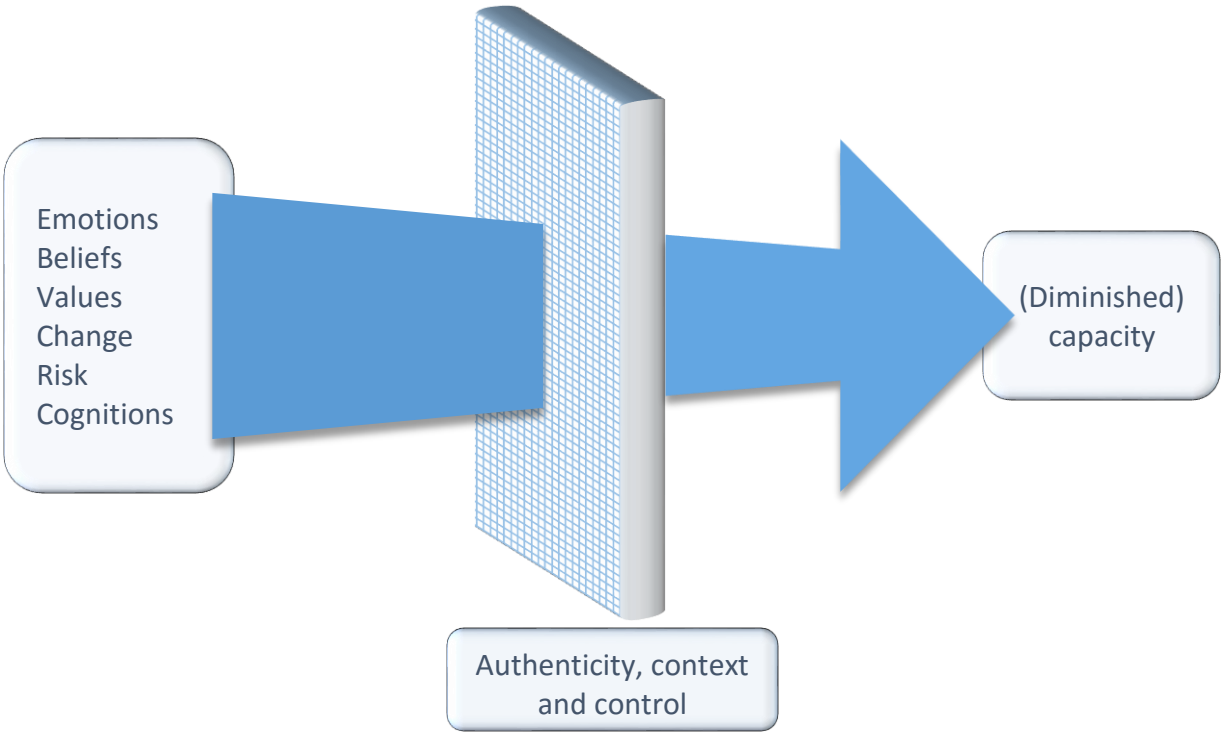

Figure 3: Capacity Assessment as Filtered through Individual's Authenticity, Context and Control

4.1.2 Involving Others: A Complex Balancing Act

Participants held strong views on whom they wished to have involved in capacity assessment and decision-making. Furthermore, choosing who to involve was deeply personal, not readily reducible to a hierarchy of family members or professionals. Instead, participants held clear views on the qualities required of involved others; namely appropriate knowledge, trustworthiness and a relationship. Participants also identified a number of benefits and barriers to involving others. This section summarises these views.

A key requirement of involved others was that they held appropriate knowledge. However, what was considered 'appropriate' varied among participants; while many preferred someone with personal knowledge, others also considered professional expertise or practical skills essential. These findings complement the conflicting findings of Swartz *et al.* (2006) and Perreault *et al.* (1999), which reported that people with mental illness preferred involvement of doctors versus relatives respectively, and suggests that a reason for this conflicting finding could be related to the type of knowledge valued by the individual.

The type of decision influenced the knowledge considered important; just as research found that people preferred to leave everyday decisions to someone trusted and close (Carter, 2009, in Pathare & Shields, 2012) while delegating legal decisions to a lawyer (Amnesty International Ireland, 2009), so participants more readily endorsed the involvement of medical professionals in decisions about medication. Experience also played a role in determining whom to involve and the weight given to different forms of knowledge; some, such as Daniel, had experienced good care at the hands of mental health professionals and implicitly trusted them, others, such has Grace, had difficulty identifying even one person due to her negative experiences.

More than knowledge however, participants emphasised the need for trust and for those involved in capacity assessment and decision-making to exhibit "human" qualities such as empathy, kindness, listening skills, transparency and an open mind. By and large participants wanted the involvement of others to be built upon a relationship, developed over time and fostered on mutual respect and consideration.

Most participants wished to involve more than one person. Often this was a combination of someone with medical expertise and someone else with personal

knowledge. This was driven by a hope that it would facilitate a balanced understanding of the participant and their situation, leading, presumably, to more balanced decisions. Mutual support for themselves and each other was also cited, perhaps to balance the fear of being a burden.

While the inclusion of a professional was considered beneficial by many participants, this was not endorsed by all. The traditional reliance on legal, medical or psychological professions to determine capacity privileges the forms of rationality valued by these professions; objective, impartial, and empirically-driven. This is not to say this approach is "wrong" – it is simply not shared by all participants. The depth of participant discussion on the qualities, capabilities and selection of those to be involved suggests a belief that if this is done 'right,' 'right' decisions will follow. Participants reference this when they speak about how 'being known' by others leads to help-seeking behaviour; although they may not like the decision, they have faith that the other has incorporated their dislike into decision-making.

Stigma, social isolation, and a feeling of having "no one to rely on" was evidently a fairly common occurrence among participants, who provided numerous reasons as to why they would not involve certain people. Many of these reasons arose from past negative experiences; disconnection from services, feeling betrayed by those previously trusted, abuse, or simply feeling there was no one available who met all the required qualities. Conversely, there was a concern that others could be "too close," feel burdened or overwhelmed by the responsibility, or that the individual would become dependent on the other person. These experiences likely influenced the number of participants who cited the need for advocates or safeguards.

In sum, participants felt they should dictate who to involve, at what stage (assessment or decision-making), and with what decisions. Participants wanted those involved to know them, their illness and their situation, to be trustworthy, and someone with whom they had a relationship. Often, participants wanted to involve more than one person. Yet barriers to involving others also suggest a need to focus on relationship building and rigorous safeguards.

4.1.3 Decision-Making during Diminished Capacity: Intricate and Idiosyncratic

Three observations are drawn from participant preferences for decision-making during periods of diminished capacity. First, most participants appreciated some support with decision-making, irrespective of capacity. Second, although most participants wanted their wishes to be accommodated, a large proportion wanted these overridden should they prove 'risky'. Finally, participant preferences for principles and models guiding decision-making during diminished capacity were highly individualised and multifaceted.

Participants expressed a clear preference for involvement in, and authority over, decision-making at *all* levels of capacity. However, like the findings of Adams *et al.* (2007), Hamann *et al.* (2005) and Mahone (2008), many preferred a collaborative decision-making style over complete autonomy. Participants expressed appreciation for every-day, informal support; someone to talk to, "share a cuppa with," and to a lesser extent, seek advice from. This informal social and emotional support may form the backbone for relationship-building with involved others. Conversely, more participants endorsed an advice-giving role and shifted emphasis from sole decision-making to a negotiated process when discussing preferences when capacity is diminished.

Despite their preference for involvement and the negative experience of exclusion, several participants wanted their decisions to be overridden if they proved risky. This stance echoes the risk-relative model advocated by Buchanan and Brock (1989; 1991), a controversial finding in light of the debates over this approach, but perhaps in line with case law (Oliver, 1997) and clinical practice (Kim *et al.*, 2011; Wilks, 1999). Why is this? Three explanations are possible:

1. Respondents have internalised the rhetoric of "dangerousness" pervading the MH(CAT) Act. The language employed by some participants suggested this; Cate requested her decisions be overridden if she posed "a risk to myself," while Kim extended these grounds to include risk "to others."
2. Participants have co-opted paternalistic models of care, referenced by their assertions that it was "for my own good," "they know better" and they "care."
3. Participants believe they would have anticipated and managed risks if competent; conversely incapacity was characterised by an inability to do so, requiring external intervention.

Regardless of the underlying reason, not all participants sanctioned this overriding of their wishes; those who had experienced this often found it a disempowering and demeaning experience.

Finally, participants expressed highly individualised, contextualised preferences for how they would want decisions to be made should they lack capacity – so much so that finding patterns or trends proved impossible. Similar to the studies reported by Amnesty International (2009; McDaid & Delaney, 2011) and Myron *et al.* (2008) all participants wanted support with decision-making – whether practical, emotional or problem-solving – and for current wishes to be heeded in the first instance, perhaps through the application of supported decision-making. However, participant preferences beyond this were individualised to the nth degree. Participants differed on who should make decisions, what principles should guide decision-making, whether all decisions should be made in the same way and by the same person(s), and whether there should there be an 'override clause.' While some wanted decisions to be made based on their (future) best interests, others felt best interests could only be assessed through an understanding of past views. Some wanted to retain control by having the 'final say' or via advance directives stipulating decisions, others hoped to nominate surrogates to undertake a form of substituted judgement, while yet others wanted to leave all decision-making to "experts."

Personality and experience played a major role in participant preferences. Cassandra's experience of unwellness was such that she wanted an advance directive (past wishes) to stipulate which wishes to be heeded and which to be overridden should she become unwell. Daniel's relief at abdicating decision-making to 'experts' when unwell meant he felt comfortable deferring to them again in the future, whereas Brooke's negative experience of others deciding for her meant she would only devolve decision-making to someone who would advocate for her wishes.

In conclusion, although supported decision-making was endorsed by most participants, no single model or principle guiding decision-making beyond this was promoted. Instead, participants had highly personalised preferences based on their own values and past experiences. Preferences were not static, often changing as new lines of enquiry were pursued or new viewpoints considered. Models for decision-making

during periods of diminished capacity therefore need to allow not only for differences between individuals, but also for a high degree of fluidity as people change.

4.1.4 Relational Autonomy

The importance of relational autonomy in both assessment and decision-making was an unexpected finding.

As discussed in Section 1.1.2 and 1.4, relational autonomy draws attention to Western medicine's failure to account for social influences and collaborative decision-making in its focus on individual autonomy (Kontos *et al.*, 2013; Martin & Hickerson, 2013; Pellegrino, 1994; Sjöstrand, 2013; Tauber, 2003). Proponents of relational autonomy argue that focussing on individual decision-making can be "isolating and burdensome" (Blackhall *et al.*, 1995, p. 824; Gostin, 1995), instead arguing for a stance in which decisions are placed "in a broader context where social influences are important in value formation, decision-making, and consideration of the impact of one's decisions on others" (Kontos *et al.*, 2013, p. 107; Sjöstrand *et al.*, 2013) and where the involvement of others is considered integral to autonomy (Ho, 2008).

Several findings from this study support the importance of relational autonomy:

- Positive regard by others facilitated participants' sense of capacity whereas doubt undermined it; just as Marjorie and Cassandra spoke about the benefits of positive regard, so Cate and Anthea described how examination of their decision-making undermined their confidence. Transference between the compromised individual and their support people could also facilitate or undermine one's capacity; Julia described how the powerlessness of those supporting her destabilised her own competence.
- Some participants, such as Warren, felt that consideration of a decision's impact on others indicated competent decision-making; conversely, failing to consider these impacts indicated possible incapacity. Alternatively, this could reference a distinction between *competent* versus *mature* decision-making; some participants alluded to this higher, pro-social standard when pronouncing that decision-making involved an element of 'adulthood.'

- Few participants wanted to make decisions alone even when they had full capacity. In fact, Cate expressed a view that having "discussed [my decision], with family or whoever" was an indication of retained capacity.
- Although participants considered interpersonal dynamics generally beneficial to decision-making, some spoke of "being led" or bullied by others. This suggests gradations in the influence exerted by others and the potential for considering another's viewpoint to shade into manipulation and control.
- Finally, participants acknowledged that interpersonal relationships can also influence involved others. In particular, people can be "too close" or "don't wanna believe." For example, Damon spoke about how, in order to preserve their relationship, his mother would likely acquiesce with his (compromised) decisions even if they are not in his interests or what he (in hindsight) feels should be done.

This highlights an important but often unacknowledged consideration; that decision-making capacity could be at least partially relational in nature and, therefore, in capacity assessment and decision-making, attention needs to be paid to the impact of relationships, both on the compromised individual and on involved others.

4.2 Research Limitations

Interpretation of the findings of this study should take into account the following research limitations: sampling methodology and size, group effects and the possibility of bias.

4.2.1 Sampling Limitations

The use of pre-existing groups as recruiting grounds has limitations. This is a very small subset of the wider group of people with a diagnosis of mental illness and those who attend groups may differ significantly from the greater population of people with a mental illness. For example, because all groups met during working hours, those

employed fulltime were inadvertently excluded. Group attendees may also hold different views on collaborative decision-making than those who do not participate in groups. Further, among those approached, a smaller subset chose to participate in the research project. They too could differ significantly from the wider population of people with mental illness; Rauktis *et al.* (1998) comment that the same group of mental health consumers attend the majority of mental health committees and research activities, limiting the breadth of information and participation achieved.

The decision to exclude current psychiatric inpatient facilities as recruitment sites may seem counterintuitive; a key premise of this research was that people do not lack capacity simply by virtue of mental illness or psychiatric hospital admission. Research invitations could have been extended to everyone accessing mental health services, however, this would have required "weeding out" those who lack capacity, usually by other health practitioners on behalf of the researcher (Warren & Allen, 1997, cited in Peterson, 1999), introducing further sampling bias.

The current sample only recruited two participants who identified as Māori (7.1%), despite attempts made through a Māori cultural group. While this reflects the population makeup of Dunedin, it does not reflect that of Aotearoa New Zealand. Nor did any participants identify as Pasifika or any other ethnicity. Although it is expected that culture influences one's views, the current research did not allow for comparison of cultural groupings.

Diagnosis was furnished by participants and was not formally confirmed. Nor were several diagnoses represented (such as eating disorders or substance misuse disorders). This could have implications as to the validity of diagnostic comparisons.

The small sample size of only 28 participants and sampling biases identified above makes inferences as to the generalisability of these findings to wider populations untenable. This is not a major shortcoming of this project, which aimed to ascertain the range of views of people with mental illness, however sampling limitations allow the possibility some views were not included.

4.2.2 Group Effects

The use of pre-existing groups for focus groups could have contributed to group effects, such as social influence, free riding and the influence of information.

Social influence refers to factors such as evaluation apprehension (reluctance to share ideas due to fear of negative appraisal), group normativity or polarisation, and the effect of dominant participants on others' contributions. The use of pre-existing groups also increased the risk that participants may feel uncomfortable sharing views due to established social hierarchies (Fern, 2001). Conversely, in their research on focus groups with people with mental illness, Rauktis *et al.* (1998) observed that participants were largely supportive and accepting of difference; a similar effect was found in this research project. Free riding – a decrease in productivity due to a diffusion of responsibility (Fern, 2001) – was minimised by small group size and by facilitator strategies to ensure all contributed. However there were always quieter individuals or those who tended to agree with statements made by previous members, sometimes contradicting their own prior statements. Finally, persuasive arguments, social influence, and discussion content may have had a bearing on individual attitudes and which ideas were raised (Fern, 2001). Thus, while individual views were extrapolated from focus groups, it was often difficult to separate individual from group data, with participants frequently shifting their positions over the course of discussion.

4.2.3 Limitations Related to Research Questions, Data Collection and Data Analysis

Discussion centred on participant recall or visualisation of scenarios where their capacity may be diminished. However, there is evidence that one's recall is not always accurate (Bryman, 2012) and that people tend to be more accepting of 'unpleasant' experiences in their past than in their present or future (Doherty, 2011, in Craigie, 2013). Thus, participants may have endorsed interventions not necessarily reflective of their views when confronted with reality, a paradox acknowledged by some participants such as Gabe. This is an unavoidable outcome while people with diminished capacity are excluded from research participation and means this research itself privileges past selves over other (potentially compromised) selves.

When counting instances of themes raised by individual and group members, only those instances where a theme was raised or qualitatively commented on by a participant were counted. Non-verbal and short, one word indications of agreement or disagreement (such as "mmmhmmm") were not counted. This was done for two reasons:

1. As only audio recordings of discussion were taken, non-verbal cues were lost,
2. While some short utterances clearly indicated assent or dissent, most could not be so easily defined.

However, counting the number of participants who contribute to discussion on a view cannot accurately indicate the degree to which this idea was shared by participants as a whole. This is because it excludes instances where an individual shares an idea but does not raise it, where people agree or disagree but maintain silence, where people may hold a specific view but do not think of it at the time or have an opportunity to raise it, and participants who are naturally more reticent. Similarly, the observation that participants often held multiple views, shifting in response to discussion content, resulted in complex, overlapping themes and subthemes.

These limitations in data collection, combined with the sampling limitations described above, also affected data analysis; statistical analysis to assess the *depth* of participant views could not be conducted to the extent hoped. Again, as this research sought to explore the *range* of views held this is not a significant shortcoming. Future research could quantitatively explore the depth of these views.

4.3 Implications for Policy and Practice

Despite the research limitations some implications for policy and practice can be identified. Two types of recommendations can be made: those relating to the "coal face"

tasks of capacity assessment and decision-making, and those relating to preparatory work planning for the possibility of diminished capacity.

4.3.1 Recommendations for Legislation and Policy

Recommendations at the "coal face" of capacity relate to policy and legislation directing capacity assessment and decision-making during periods of diminished capacity.

Capacity assessment. First, this research supports the proposition that capacity assessment is not a neutral, value-free exercise that can be undertaken in a standardised way by an objective other. Each individual in this study had a slightly different view on what it meant to have decision-making capacity and how to determine whether this was diminished. These findings reject the notion that a person lacks capacity by virtue of being subject to compulsory mental health treatment, as seems to be implied by the MH(CAT) Act, or that capacity is all-or-nothing as suggested by provisions of the PPPR Act.

Instead, the conclusion that capacity is not just socially, but also individually constructed suggests that capacity assessment should include a comprehensive understanding of the individual and their context. Ideally, this understanding is grounded in close interaction with the individual, suggesting that this cannot be conducted by someone simply by virtue of their professional membership (i.e. a medical professional). While some expert knowledge is considered important, this is tempered by participants' desire for a collaborative engagement between assessors, themselves, and those networks with whom they are connected. Rather than a dichotomous 'yes/no' answer to the question, "does this individual have capacity?", respondents point to a different question: "Why are there doubts about this person's capacity? Is it because I don't understand them or are barriers limiting the exercise of capacity?" Respondents preferred that all involved work together to develop an understanding of them in their context, and to facilitate the building of capacity.

Pragmatists will undoubtedly roll their eyes at this finding; ultimately there are times when a 'yes/no' answer is required. However, opening with this approach is

ultimately more empowering, more respectful, and more in keeping with the notion of partial incapacity.

Involving others. Legislative approaches must respect the possibility that the compromised individual may want more than one person involved, that these people may not necessarily be family members or professionals, and that who is involved may change depending on the situation or decision. Thus, the deferral to medical professionals for capacity assessment, the appointment of a single welfare guardian under the PPPR Act and the requirement under the MH(CAT) Act for consultation with family members does not accurately reflect the range of participant preferences. Legislation also needs to consider accessible procedures for review as people's circumstances and preferences change and for dispute resolution processes in the event that support networks disagree, ideally permitting individuals to decide in advance how disputes will be settled.

Decision-making. Participants' overwhelming preference for some degree of involvement in decision-making, irrespective of capacity, suggest that models of supported decision-making should be further explored, strengthened, and ultimately enshrined in legislation.

However, respondents' rejection of a "one-size fits all" approach for decision-making and their fluid and highly individualised preferences suggests that an understanding of the individual is essential for decision-making when capacity is diminished. Although the risk-aversive, best interests approach favoured by the MH(CAT) Act, the PPPR Act and current practice was endorsed by many participants, this was often seen as a "last resort," with participants identifying a range of approaches they preferred in the first instance.

Accordingly, legislation needs flexibility to incorporate differences in preferences for decision-making when capacity is diminished. This flexibility needs to allow not only for differences between individuals, but also individual changes in preference. At the same time, legislation must also provide safeguards for those whose preferences are unknown and those who want to block any attempts by their unwell selves to change

their instructions. The method mandated by the H&DC Act, which provides for a menu of options, seems to fit most closely with this approach, while advance directives seem best placed to allow people to plan for incapacity. However, neither of these is well-placed to allow for fluidity in participant preference, and more needs to be done to strengthen the powers of advance directives so that these can be legally binding for those that want them to be, while allowing others to specify when they would want them overridden.

4.3.2 The Importance of Process: Recommendations for Preparatory Practice

Viewing capacity assessment, involving others, and decision-making during diminished capacity as *processes* rather than tasks allows for consideration of the work required "behind the scenes" to facilitate best outcomes. This work needs to occur on two fronts: a. working with individuals to develop an understanding of what capacity means to them and what principles they feel should guide decision-making, and b. facilitating optimum relationships with involved others.

Planning for incapacity. Findings of this research underscore the importance of planning and regular in-depth discussion with people with mental illness on how they define incapacity, who they would want involved, and how they would want decisions to be made. These discussions need to go beyond simple, concrete statements of preference (such as what medication they would or would not like prescribed), to incorporate an understanding of the values they feel should underpin assessment and decision-making. Do they want their wishes or interests to be considered in the first instance? What role should "risk" play in assessment or decision-making – for that matter, how do they define risk? Who would they want involved, in what decisions, and how? What if there is conflict; how would they want this resolved? What if in future they disagree with what they have set down now? What if what they decide now is not deemed in their best interests? Would they want these wishes overridden by another? Who? How much input do they want their "compromised" selves to have in decision-making? How might this change? Are there foreseeable dilemmas? What about unforeseeable dilemmas?

Addressing this may involve developing a form of advance directive. By going beyond simple statements of preference to explore underlying principles, these discussions may provide guidance on not just one's past wishes, but on how much these past wishes should be heeded (ultimately, this remains a person's past wishes on the applicability of their past wishes, but perhaps this is unavoidable). These discussions need to be regularly reviewed and offered to everybody, irrespective of their mental health status. While a mental health professional may facilitate them, this does not need to be the case; it is more important that nominated support people be involved. It could also be useful to develop a prompt sheet to facilitate and record conversations.

Facilitating relationships. Participants' desire to involve wider support networks in capacity assessment and decision-making, the plethora of challenges identified in doing so, and the importance of considering relational autonomy, all highlight the work that must occur to ensure involved others can fulfil the roles envisaged for them by people with mental illness.

First, mental health services need to recognise that models of service delivery may not allow for the formation, maintenance and availability of important relationships at key moments of crisis. This highlights the importance of continuity of care, both within services and between episodes of unwellness. Transfer of care at key moments, such as the transfer to the ward psychiatrist when a person becomes an inpatient, may deprive a person of access to those professionals who know them best, leaving them feeling isolated, alone, and unknown. And while discharge from the Community Mental Health Team may be appropriate, consideration needs to be given to the gap that is created, as recounted by Anthea.

Second, attention should be paid to relationship formation and maintenance, particularly between individuals and their wider support networks. Specifically, while mental health services may be better at involving informal support networks than they once were (Donnelly, 2009; Roupie *et al.*, 2000), there needs to be a greater understanding of the role of non-statutory support services, such as support workers at drop-in centres. There also needs to be an acknowledgement of the immense burden placed on informal supports during periods of diminished capacity, especially when enforcing a course of action the compromised individual does not agree to.

Accordingly, systems must not only safeguard and empower individuals with diminished capacity, but also their support people. Empowering support people might involve psychoeducation or training in rehabilitative skills (to prevent dependence). But most importantly empowerment of support people necessitates their inclusion in planning discussions, addressing any concerns they may have, and considering questions such as: do they hold contradictory views from the individual with mental illness? If so, how should this be resolved? Are there decisions they feel more or less comfortable with? What support do they need, and how can this best be provided? Have all parties considered the impact that 'difficult' (read: contentious) decisions may have on their ongoing relationship, and does this change their views on whether they wish to be involved?

4.4 Further Research

This study raises as many questions as it answers, suggesting many avenues for future research. Now that a range of views have been ascertained, the next step is to quantify and operationalise these in a way that allows for studies that gauge the prevalence of these views. From here, more specific questions could be answered: Are there cultural differences in preferences? Are there overall trends in preferences for decision-making models? Are there statistical differences in views according to diagnostic categories, and what about the views of people who fit diagnostic categories not sampled in this research, such as anorexia nervosa? Further research could also explore what exactly people want when they ask for supported decision-making or how the capacities of support people can be strengthened. Research exploring the development and implementation of a "discussion tool" as recommended above could also be useful.

4.5 Conclusion

If nothing else, this research has demonstrated that capacity is both socially and personally constructed and that people's preferences are unique, complex and fluid. While this project struggled to find order in the cacophony of participant voices, in retrospect this is hardly surprising – people will always have different opinions according to their experiences, values and beliefs.

Although the fluidity and variety of participant views was a challenge for the research project, it emphasises the importance of innovative and individualised planning with people with mental illness. Despite expectations to the contrary, all participants engaged candidly in discussion and freely considered different points of view. While some participants held more complex views than others; none had no views whatsoever. Creating systems and legislation that have the flexibility to hear these views and incorporate people's (changing) preferences is a challenge, but it could also herald a new way of working with people where intervention isn't 'pigeon-holed' according to an arbitrary assessment of incapacity.

Ultimately, what this project shows is the importance of frequent frank, respectful and validating conversations. This is not about another paperwork exercise for already overworked Community Mental Health professionals, subject to auditing (although there is a risk it may become so). It is not about a single discussion that can be "ticked off" the list of things to do. It does not even need to be done by mental health professionals or with people with mental illness. It is about process. It is about knowing what our loved ones want and making sure they know the same about us. It is a process of engagement; getting to know a person and finding out what makes them tick, who is important to them and what is important to them.

Funnily enough, it is about relationships.

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Appendix A: Ethics Approval and Consultation

Note. To protect participant confidentiality, locality approvals granted by each host facility are not provided.

University of Otago Human Research Ethics Committee

H14/092

Academic Services
Manager, Academic Committees, Mr Gary Witte

22 July 2014

Professor A Barusch
Department of Sociology, Gender and Social Work

Dear Professor Barusch,

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled "**Introducing the voices of people with mental illness into the debate on assessment and support for (in)capacity**".

As a result of that consideration, the current status of your proposal is:- **Approved**

For your future reference, the Ethics Committee's reference code for this project is:- **H14/092**.

While approving the application, the Committee would be grateful if you would respond to the following:

The Committee was of the view that the Information Sheet could be shortened and summarised and attached to the longer more detailed version if necessary.

Please provide the Committee with copies of the updated documents, if changes have been necessary.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

http://www.otago.ac.nz/healthandsafety/index.html

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

gary.witte@otago.ac.nz

jo.farrondediaz@otago.ac.nz

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor H R Campbell Head Department of Sociology, Gender and Social Work

University of Otago Human Research Ethics Committee

Amendment Letter

H14/092

Academic Services
Manager, Academic Committees, Mr Gary Witte

11 September 2014

Professor A Barusch
Department of Sociology, Gender and Social Work

Dear Professor Barusch,

I am again writing to you concerning your proposal entitled "**Introducing the voices of people with mental illness into the debate on assessment and support for (in)capacity**", Ethics Committee reference number **H14/092**.

Thank you for your e-mail of today with attached amended (shortened) information sheets. The Committee notes that you wish to include a participant outside the age-range initially proposed. The Committee accepts and approves the amendment to the age range to 18-67 in order to be able to include the individual who has expressed an interest in taking part.

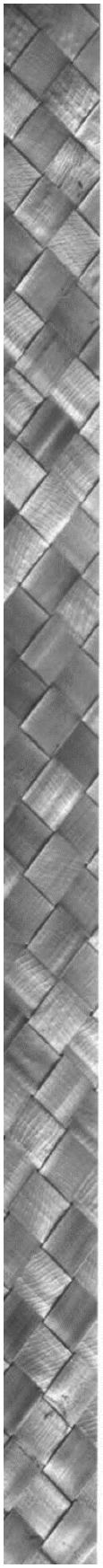
Your proposal continues to be fully approved by the Human Ethics Committee. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing. I hope all goes well for you with your upcoming research.

Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor H R Campbell Head Department of Sociology, Gender and Social Work

Ngai Tahu Research Consultation Committee



NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

Tuesday, 15 April 2014.

Professor Amanda Barusch,
Department of Sociology - Gender and Social Work,
DUNEDIN.

Tēnā Koe Professor Amanda Barusch,

Introducing the voices of people with mental illness into the debate on assessment and support for (in)capacity.

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 15 April 2014 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee notes the researchers have identified that often whanau are not included in some discussions where their involvement is vital and important.

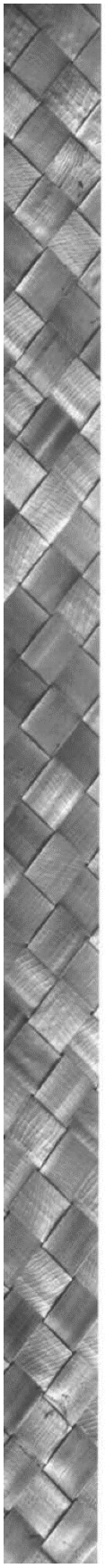
The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and The Committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 15 April 2014 to 2 October 2015.

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki



NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

Nāhaku noa, nā

Mark Brunton
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The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki

Health Research South Locality Approval

Health Research South

9/12/2014 **Project ID** 01051

Prof Kate Scott
Psychological Medicine, DSM

Dear Kate

REF: Introducing the voices of people with mental illness into the debate on assessment and support for (in) capacity.

I am writing on behalf of Health Research South to confirm that the project mentioned above has been granted approval to proceed.

According to our records:

This project is due to commence on: 9/12/2014
It is due to be completed by: 31/12/2015

If you have any questions with regards to this process, please contact me quoting the project ID shown above.

Yours sincerely

Ruth Sharpe
CLINICAL RESEARCH ADVISOR

cc.: LOUISE TRAVERS, SOUTHERN DHB
KAREN RAMSAY, SOUTHERN DHB
MARIA VAN'T KLOOSTER, SOUTHERN DHB

Health Research South
University of Otago, Dunedin School of Medicine and Southern District Health Board
PO Box 56, Dunedin 9054
Ruth Sharpe, Clinical Research Advisor, Ph: 03 470 9032 (Hosp 9032); Ruth.Sharpe@otago.ac.nz

Appendix B: Information for Participants

Focus Group Information Sheet

Ref: H14/092

Participant Information Sheet

Study title:	Introducing the voices of people with mental illness in the debate on assessment and support for (in)capacity - FOCUS GROUP PHASE -	
Principal investigator:	**Name:** Amanda Barusch **Department:** Sociology, Gender and Social Work **Position:** Professor	Contact phone number: 03 479 7951

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

This project is being undertaken as part of the requirements for a Master of Social Work. The aim is to explore the views of people who have a diagnosis of mental illness on whether there are times when they feel they are unable to make decisions on their own (this is called having "diminished capacity") and how they would want to be supported during these times.

This project will have two stages. These two phases will be put together to get a full picture of the views of people with mental illness. ***You do not need to take part in both phases and you can withdraw at any stage.*** The stages are as follows:

1. Focus Groups: We want to talk to people in groups to find out their views on the three questions below.
2. One-on-one interviews. People can also volunteer to take part in one-to-one

interviews.

This information sheet relates to the FOCUS GROUP stage.

Who are we seeking to participate in the project?

This stage of the project is open to any groups in the greater Dunedin area for people aged 18 to 65 with a diagnosis of a mental illness or personality disorder. We are approaching different groups for people with mental illness around Dunedin to ask if they are willing to be part of this research. If your group is willing, then this will form one focus group. ***You do not need to participate just because your group as a whole is.*** The researcher will meet with those who choose to participate in a space decided upon by the group; those who choose not to participate will be able to continue with their usual group activities.

People who are in one or more of the categories listed below will not be able to participate in the project because, in the opinion of the researchers and the University of Otago Human Ethics Committee, it may involve an unacceptable risk to them:-

- People who currently are assessed as having diminished capacity,
- People who are current clients of the researcher.

If you participate, what will you be asked to do?

If your group chooses to participate, the student researcher will either join your group for one of your usual sessions or meet with your group for a session outside your usual group time – this would depend on the preferences of your group.

During this session, you will first be asked to complete a short questionnaire asking for basic details. A copy of this questionnaire is attached.

Once this has been completed, the researcher will guide the group in a general discussion on three topics:

1. What you think professionals (or other people) should consider when deciding whether you are able to make decisions on your own (in other words, what professionals should consider when they 'assess capacity')
2. How much you normally want to be involved in making decisions, and how this might change (or not) if you became unwell.
3. How you would want others to be involved in making decisions if you are unable to do so yourself. In particular, who would you want to be involved, what decisions you would want them involved with, what you would want them to consider, and how you would want them to make decisions with or for you.

You may be asked to write down your views before sharing and discussing these with the group.

It is expected that this would take no longer than your usual group session. It is hoped that the researcher will meet with your group sometime between July and November 2014.

Is there any risk of discomfort or harm from participation?

It is hoped that this discussion will not be distressing to participants. However, **because it will be a group setting and open-ended questions will be used, it is impossible to predict what will be discussed and therefore to guarantee that no topics will be distressing to any participant.** In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

Please note that the student researcher works part-time at the Dunedin Emergency Psychiatric Services (EPS) and the North Community Mental Health Team. This means that while participants are excluded from the study on the basis of *currently* engaging with the researcher, you may well have contact in the future. It is likely that the researcher's knowledge of your wishes would increase the prospect of treatment respecting these wishes in a crisis.

What information will be collected, and how will it be used?

Discussion will be audio-taped and transcribed to allow the researcher to accurately recall your views. If you are not happy for the discussion to be recorded then we will arrange for someone independent to take notes.

The information collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed.

What about anonymity and confidentiality?

Focus groups are particularly sensitive to concerns around confidentiality, and you are asked to respect your normal group's code of confidentiality. You are reminded that you are free to leave the group or refrain from answering should you have concerns about confidentiality.

The transcription and notes will be anonymised to protect your identity. The notes and/or transcript will be seen by the Master's student researcher and by Professor Amanda Barusch (of the Department of Sociology, Gender & Social Work, University of Otago).

Individuals can access copies of their voice recordings, however they will only be able to request copies of interviews in which they were participants. If an individual requests a copy of their focus group recording, this will be released to the other members of that focus group, as all participants are considered to be equal and voluntary participants.

The combined data from all phases of this project may be published and will be available in the University of Otago Library (Dunedin, New Zealand). While all data will be anonymised, Dunedin is a small community, and it is possible that participants may be identifiable by quotes used in publication. You will be given an opportunity to review a draft of the thesis.

If you decide that you do not want a quote attributable to you to be included, you can ask for this to be removed.

The student researcher will meet with your group to talk about the results of the project and you will be able to provide feedback on a draft of the research. It is hoped that this will happen in about February 2015. The final thesis should be completed by June 2015; you are most welcome to request a copy of the results and to read to the completed research if you wish.

Your safety and that of others is paramount. This means that your confidentiality may be overridden if, for example, you disclose something that compromised your safety or that of another. In the unlikely event that this needs to happen, the researcher will talk to you about what needs to be disclosed, why, and who to, unless it is considered that risk would be increased by doing so.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project at any time and without any disadvantage to yourself.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

Name: Maria van't Klooster **Position: Student Researcher** **Department: Sociology, Gender and Social Work**	Contact details: Maria.vantklooster@student.otago.ac.nz
Name: Amanda Barusch **Position: Principal Researcher** **Department: Sociology, Gender and Social Work**	Contact phone number: 03 479 7951

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Individual Interview Information Sheet

Ref: H14/092

Participant Information Sheet

Study title:	Introducing the voices of people with mental illness in the debate on assessment and support for (in)capacity - INTERVIEW PHASE -	
Principal investigator:	Name: Amanda Barusch Department: Sociology, Gender and Social Work Position: Professor	Contact phone number: 03 479 7951

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

This project is being undertaken as part of the requirements for a Master of Social Work. The aim is to explore the views of people who have a diagnosis of mental illness on whether there are times when they feel they are unable to make decisions on their own (this is called having "diminished capacity") and how they would want to be supported during these times.

This project has two stages. This is the SECOND stage. This stage will involve one-on-one interviews. Anyone can volunteer to take part in one-to-one interviews.

Who are we seeking to participate in the project?

This stage of the project is open to anyone who belongs to the host group approached for the focus group stage and who volunteered to take part in interviews. We may not be able to interview everyone who wants to be part of this stage. If this is the case, we will select

people from the following two groups;

1. People who did not take part in the focus groups, or
2. People who took part in the focus groups and who expressed ideas that are different from the wider group or who had particularly strong views.

We will also pay attention to what diagnoses people have, as people may have quite different views depending on their diagnosis.

People who are in one or more of the categories listed below have not been selected to participate in the project because, in the opinion of the researchers and the University of Otago Human Ethics Committee, it may involve an unacceptable risk to them:-

- People who currently are assessed as having diminished capacity,
- People who are current clients of the researcher.

If you participate, what will you be asked to do?

If you choose to participate, you will be asked to meet with the researcher for a one-to-one interview.

If you did not take part in a focus group, you will first be asked to complete the same short questionnaire as they did asking for details such as your age, ethnicity, diagnosis and a few questions relating to your social situation. A copy of this questionnaire is attached.

Once this has been completed, the researcher will then talk with you and explore your views on the following topics:

1. What factors you feel professionals (or other people) should take into consideration when assessing whether you are able to make decisions on your own (in other words, what professionals should consider when they 'assess capacity').
2. How you normally want to be involved in making decisions, and how this might change (or not) if you became unwell.
3. How you would want others to be involved in making decisions if you are unable to do so yourself. In particular, who would you want to be involved, what decisions you would want them involved with, what you would want them to consider, and how you would want them to make decisions with or for you.

In particular, the researcher wants to find out *why you feel the way you do* about these issues. The interview will explore these views in a non-judgemental way.

It is expected that the interview will take no longer than an hour, however, because of the open-ended discussion, some interviews may last longer than others. It is hoped that the researcher will meet with you sometime between July and November 2014.

Is there any risk of discomfort or harm from participation?

It is hoped that this discussion will not be distressing to participants. However, **because it open-ended questions will be used, it is impossible to predict what will be discussed and therefore to guarantee that no topics will be distressing to any participant.** In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

Please note that the student researcher works part-time at the Dunedin Emergency Psychiatric Services (EPS) and the North Community Mental Health Team. This means that while participants are excluded from the study on the basis of *currently* engaging with the researcher, you may well have contact in the future. It is likely that the researcher's knowledge of your wishes would increase the prospect of treatment respecting these wishes in a crisis.

What information will be collected, and how will they be used?

Discussion will be audio-taped and transcribed to allow the researcher to accurately recall your views. If you are not happy for the discussion to be recorded then we will arrange for someone independent to take notes.

The information collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed.

What about anonymity and confidentiality?

The transcription and notes will be anonymised to protect your identity. The notes and/or transcript will be seen by the Master's student researcher and by Professor Amanda Barusch (of the Department of Sociology, Gender & Social Work, University of Otago).

Individuals can access copies of their voice recordings, however they will only be able to request copies of interviews in which they were participants. If an individual requests a copy of their focus group recording, this will be released to the other members of that focus group, as all participants are considered to be equal and voluntary participants.

The combined data from all phases of this project may be published and will be available in the University of Otago Library (Dunedin, New Zealand). While all data will be anonymised, Dunedin is a small community, and it is possible that participants may be identifiable by quotes used in publication. All endeavours will be made to avoid using quotes that may render the individual identifiable. You will be given an opportunity to review a draft of the thesis. If you decide that you do not want your views to be part of the research, or you do not want a quote attributable to you to be included, you can ask for this to be removed.

The student researcher will meet with your group to talk about the results of the project and you will be able to provide feedback on a draft of the research. It is hoped that this will happen in about February 2015. The final thesis should be completed by June 2015; you are most welcome to request a copy of the results and to read to the completed research if you wish.

Your safety and that of others is paramount. This means that your confidentiality may be overridden if, for example, you disclose something that compromised your safety or that of another. In the unlikely event that this needs to happen, the researcher will talk to you about what needs to be disclosed, why, and who to, unless it is considered that risk would

be increased by doing so.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project at any time and without any disadvantage to yourself.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

Name: Maria van't Klooster **Position: Student Researcher** **Department: Sociology, Gender and Social Work**	Contact details: Maria.vantklooster@student.otago.ac.nz
Name: Amanda Barusch **Position: Principal Researcher** **Department: Sociology, Gender and Social Work**	Contact phone number: 03 479 7951

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix C: Participant Questionnaire

Introducing the voices of people with mental illness into the debate on assessment and support for (in)capacity.

– QUESTIONNAIRE –

What is your age? .....

What is your gender? MALE / FEMALE

What is your ethnicity? .....

Do you have a diagnosis of mental illness? YES / NO

If yes, please specify. .....

Please briefly describe your living situation *(i.e. live alone, flatting, live with whānau/family, live with spouse/partner)*

.....

Please list who you consider to be part of your support network *(i.e. mum, husband, friend. No names please)*.

....

....

....

Have you ever been under the Mental Health Act? YES / NO

Have you ever been assessed as lacking capacity (that is, as being unable to make decisions for yourself)? YES / NO / DON'T KNOW

If yes, did you agree with this assessment? YES / NO

If no, do you think there are times that you *should* have been assessed as lacking capacity? YES / NO

Can you identify one or more people who you feel you would trust to make decisions on your behalf if you couldn't? YES / NO

If so, who? (*(i.e. mum, husband, doctor, friend. No names please)* .....

Has this been legally arranged (like through an Enduring Power or Attorney)? YES / NO

Are there any other questions or comments you would like to make?

……

……

……

……

Are you willing to be contacted for stage two of the research? *(please note you can change your mind about this at any time)* YES / NO

If yes, please can you give your name and contact details *(please note that this information will only be kept in order to contact you, and any personal information will be destroyed).*

Name: ……

Contact Details: ……

THANK YOU FOR TAKING THE TIME TO FILL THIS OUT

Appendix D: Consent Forms

Focus Groups

Introducing the voices of people with mental illness in the debate on assessment and support for (in)capacity

- FOCUS GROUP PHASE –

Principal Investigator: *Professor Amanda Barusch, amanda.barusch@otago.ac.nz, 03 479 7951*

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:

……..

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that as a participant I will complete a short questionnaire and take part in a focus group discussion.
7. I know that the questionnaire and focus group will explore:
    a. How I feel professionals (or other people) should decide whether I am able to make decisions on my own (in other words, what professionals should consider when they 'assess capacity')
    b. How I want to be involved in making decisions when I am well, and how this might change if I were unable to make decisions on my own

c. How I would want others to be involved in making decisions if I were unable to do so myself. In particular, who I would want to be involved, what I would want them to consider, and how I would want them to make decisions with or for me.

I understand that the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which group discussion develops. In the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.

8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
10. I understand that the results of the project may be published and be available in the University of Otago Library, but that I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study.
11. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant:	Date:

Signature and name of witness:	Date:

Individual Interviews

Ref: H14/092

Introducing the voices of people with mental illness in the debate on assessment and support for (in)capacity

- INTERVIEW PHASE –

Principal Investigator: *Professor Amanda Barusch, amanda.barusch@otago.ac.nz, 03 479 7951*

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:

……..

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that as a participant I will be asked to take part in a one-on-one interview with the student researcher.
7. I know that the interview will explore:
    a. The reasons behind any particular factors I feel professionals (or other people) should take into consideration when assessing whether I am able to make decisions on my own (in other words, what professionals should consider when they 'assess capacity')
    b. The reasons behind how I want to be involved in making decisions if I were unable to make decisions on my own
    c. The reasons behind any particular ways I would want others to be involved in making decisions if I are unable to do so myself. In particular, who would

I want to be involved, what I would want them to consider, and how I would want them to make decisions with or for me.

The precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. In the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I know I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.

8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
10. I understand that the results of the project may be published and be available in the University of Otago Library, but that I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study.
11. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant:	Date:

Signature and name of witness:	Date:

Appendix E: Handout for Participants

Preparing for times when you need support to make decisions

At the moment, there are three key laws that may apply when you are unable to make decisions on your own:

The Protection of Personal and Property Rights Act (the PPPR Act)

Under this law, you can choose to appoint someone to help make decisions if you are unable to do so on your own in the future.

- You can appoint one person to help make decisions about things like medication and where you live. This person is called a Welfare Guardian. This person would only be able to make these decisions for you if you have been assessed to 'lack capacity' – that is when a doctor has said you can't make decisions on your own.
- You can also appoint the same or another person (or an organisation) to help make decisions about money and property. This person is called a Property Manager. This person could start making decisions for you straight away, or you could make it so they can only step in if you have been assessed as lacking capacity.

You get to choose who these people are. Appointing these people needs to be done by a lawyer, so it costs money, but you could get legal aid. If you do it in advance it is a relatively straightforward process. But if it needs to be done when are already unable to make decisions on your own, then it is a longer process and someone has to apply to the court on your behalf.

If you have already a Welfare Guardian someone and later you are sectioned under the Mental Health Act (the MHA), then that person could agree to treatment on your behalf. But if they refuse consent then the doctor could still use the MHA to override this. The person you have appointed cannot agree to Electro-Convulsive Treatment (ECT) on your behalf.

The Health and Disability Commission Act

Under this law, you can write an *Advance Directive*. This is a written document where you say what sort of treatment you would like should you be unable to make decisions on your own. Some people include this as part of their WRAP plan. Advance Directives are not 'legally binding'; this means that the medical team does not have to follow your wishes if you are under the Mental Health Act and they feel it is not in your best interests to do so.

The Mental Health Act (the MHA)

If you are under the Mental Health Act, the medical team has to talk with you and your family about your treatment, including whether you stay in hospital and what medication you are on. But for the first month or so, psychiatrists have the final say unless you appeal

this. After this time, the psychiatrist has to apply to the court for a Compulsory Treatment Order and a judge makes the final decision. Decisions are usually limited to things like medication and whether you should be in hospital; if you need support with other decisions like money, then this law would not apply (for example it cannot appoint someone to deal with the bank for you or help you plan how you spend your money).

The Mental Health Act cannot be used to plan for future times you become unwell; this would need to be done through one of the other two laws above. But it may be useful to talk to your friends, family and/or mental health team about what you would like if you were sectioned under the Act.

For more information…

It is a good idea to think about writing an advance directive and to consider appointing someone under the PPPR Act. For more information, you could contact the following people:

- Your local Citizens' Advice Bureau (471 6166)
- The Dunedin Community Law Centre (474 1922)
- Your mental health team

Complaints?

This discussion may have brought up unpleasant experiences. If you are not happy with the care you, a friend or family member have received in relation to a mental health issue, it may help to first:

- Talk the issue over with a support person or an advocate.
- Talk to your mental health service provider.

If you are not happy with how you have been treated you can make a complaint to the manager of the service you are talking about or to the Southern District Health Board Patient Affairs office (474 0999).

If you are not happy with how your complaint has been dealt with, you may be able to make a complaint to the Health and Disability Advocacy Service (479 0265 / 0800 555 050).

If your complaint relates to a breach of your rights while under the Mental Health Act, you can contact a District Inspector (these are lawyers appointed to make sure the Mental Health Act is followed according to the law). Your local Community Law Centre, Citizens Advice Bureau, or Mental Health Service Provider should be able to give you some advice on how to contact these. You can also find an up to date list at http://www.health.govt.nz/publication/guidelines-role-and-function-district-inspectors

Appendix F: Guide Questions

Note. These guides provide an overview of topics discussed and sample questions. Discussion was led by participants and therefore topics and questions not listed in these guides but deemed relevant to the research questions were also pursued. The exact wording in these guides was not used, questions were not asked in the same order and some questions were not asked at all.

Focus Group Guide Questions

Defining and assessing capacity:

Listen for:

- who involved,
- what should be asked/looked for,
- impact of emotionality,
- past vs present values,
- risk-relative vs decision-specific.

Lead in questions:

Imagine you have been asked to make an important decision. It could be about where you live, what you spend your money on, or what medication you take. But someone has suggested that you aren't able to make that decision on your own. How would someone talking to you be able to know if you were able to make that decision?

- What should they be asking you?
- What should they be looking for in your answers?
- Should they be talking to anyone else? If so, who?
- What if people disagree whether or not you can make this decision. Who would make the final judgement as to whether or not you can do it alone. How would they decide this?

Emotionality: What if you are really upset/happy/scared. Do you think this would affect your decision-making? What should the person doing the assessment do in this case?

Past vs present: What if all your life you said you want one thing, and now suddenly you want something different – should that be considered a sign you can't make decisions on your own?

Risk-relative or decision-specific: Say someone had a decision where one option was more 'risky' than the other; for example they had to choose whether to move into a beautiful new house or to be homeless, and they chose to be homeless. Should a decision be questioned more if it is 'risky' than if it is a 'safer' decision? (in other words, should the *outcome* of the decision be a factor in deciding whether they were able to make that decision on their own). Example: safe home vs. homesless. Choosing what to eat vs. anorexia.

Decision making preferences:

Listen for:

- Preference for information vs. involvement
- Anyone else involved?
- Differences depending on situation?
- Differences when unwell?

Lead in questions:

Normally, how much do you like to be involved in decision-making about your life?

Are there some decisions that you usually don't like to make on your own? Who would you talk to about these decisions?

Are there times when this might change? Tell me about these. How would you like to be involved in decision-making during these times?

Do you think you would feel the same way as you do now during these times?

Decision-making models

Listen for:

- Wishes vs interests
- Who involved
- Surrogate, substituted judgement, advance directives.
- Past vs present wishes

Lead in questions

Now imagine that for whatever reason you were unable to make decisions on your own. Some of you may have experienced this, others may not. Have these times been useful? Not? If someone was making a decision with you or for you, how would you want them to do that / how would you want decisios to be made?

- How much would you want to be involved?
- Who else would you want to have involved?
- What level of involvement would you want this person/these people to have?
- What if the people supporting you disagreed? Who should have the final say?
- What sort of decisions would you want people to be involved with?

Wishes vs interests: What if what you wanted was not good for you, would you want people to respect your wishes regardless or would you want them to do what is best for you (dementia scenario)

Surrogate/supported/substituted:

X----------X----------X

Surrogate Supported Substituted

Would you want them to make the decision for you, tell people what they think you would usually want, or help make the decision with you?

What if you and the person supporting you disagreed, what should happen then?

Past vs present wishes: Imagine if you usually said that you never ever wanted to live in Gore, but now suddenly you have decided you couldn't live anywhere else. Should the person act based on what you used to want, or what you want now?

Individual Interview Guide Questions

Defining and assessing capacity:

Listen for:

- who involved,
- what should be asked/looked for,
- impact of emotionality,
- past vs present values,
- risk-relative vs decision-specific.

Lead in questions:

Imagine you have been asked to make an important decision. It could be about where you live, what you spend your money on, or what medication you take. But someone has suggested that you aren't able to make that decision on your own. How would someone talking to you be able to know if you were able to make that decision?

- What should they be asking you?
- What should they be looking for in your answers?
- Should they be talking to anyone else? If so, who?
- What if people disagree whether or not you can make this decision. Who would make the final judgement as to whether or not you can do it alone. How would they decide this?

Authenticity: Do you think there are times people say they want one thing but not really mean it / make decisions that aren't genuinely theirs? What sort of factors do you think influence this / Could there be internal or external things influencing their decisions? How would you or someone else know? (look for influence of others, influence of illness, changes over time, not based in reality)

Emotionality: What if you are really upset/happy/scared. Do you think this would affect your decision-making? What should the person doing the assessment do in this case?

Values / beliefs: What if what you wanted was based on something that was important to you but that other people thought was unusual. For example, some people with anorexia think it is more important to be thin than to be healthy. What does this mean for their ability to make decisions?

Past vs present: What if all your life you said you want one thing, and now suddenly you want something different – should that be considered?

Risk-relative or decision-specific: Should the *outcome* of the decision be a factor in deciding whether they are able to make that decision on their own? Say someone had a decision where one option was more 'risky' than the other; for example they were weak and frail and had lots of falls, and they had to choose whether to live at home alone or go into care. Should they examine a decision more if it is a 'risky' decision than if it is a 'safer' decision? (in other words, should the *outcome* of the decision be a factor in deciding whether they were able to make that decision on their own). Examples: anorexia, safe house vs homeless.

Decision making preferences:

Listen for:

- Preference for information for involvement
- Anyone else involved?
- Differences depending on situation?
- Differences when unwell?

Lead in questions:

Normally, how much do you like to be involved in decision-making about your life?

Are there some decisions that you don't like to make on your own? Who would you talk to about these decisions?

Are there times when this might change? Tell me about these. How would you like to be involved in decision-making during these times?

Do you think you would feel the same way as you do now during these times?

Decision-making models

Listen for:

- Wishes vs interests
- Who involved
- Surrogate, substituted judgement, advance directives.
- Past vs present wishes

Lead in questions

Now imagine that for whatever reason you were unable to make decisions on your own. Some of you may have experienced this, others may not. I want you to think about how you would want decisions to be made with or for you during these times.

First seek experiences already had – what was useful, what wasn't?

- How much would you want to be involved? Are there things you would want more/less input into?
- Who else would you want to have involved?
- What level of involvement would you want this person/these people to have?
- What if the people supporting you disagreed? Who should have the final say?
- What sort of decisions would you want people to be involved with?

How much would you want to be involved?

Involvement of others:

Who would you want to be involved, and in what role. Would you want the same people involved in deciding you weren't able to make a decision involved in making decisions.

X----------X----------X

Surrogate Supported Substituted

Would you want them to make the decision for you, tell people what they think you would usually want, or help make the decision with you?

What if you and the person supporting you disagreed, what should happen then?

What problems might there be with involving others?

What benefits might there be to involving others?

Wishes vs interests: What if what you wanted was not good for you, would you want people to respect your wishes regardless or would you want them to do what is best for you?

Past vs present wishes: What if what you want changes? Should the person act based on what you used to want, what you want now, or what they think you might want in the future? Imagine if you usually said that you never ever wanted to be a paraplegic. But now you have had an accident and the only way to save you is to amputate your legs.

Advance directives / Ulysses Agreements: Some people have talked about creating a sort of 'living will' where they would specify what they want in certain circumstances. Do you think this is a good idea? What would you write in your living will? Who would you want to enact this? Can you see and problems with this? What if you changed your mind? What if there were circumstances you hadn't considered? Would you want your AD to be overridden?